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Feeling lonely and anxious

A cross – sectional investigation of social networks and support in first episode psychosis

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SERVICE-EVALUATION PROJECT AND MAIN RESEARCH PROJECT

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Thesis submitted in partial fulfilment of the degree of
Doctorate in Clinical Psychology

Institute of Psychiatry, King's College London

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Part 1: Main Research Project

Feeling lonely and anxious – a cross –
sectional investigation of social networks
and support in first episode psychosis

Supervisors:

Professor Elizabeth Kuipers & Dr. Juliana Onwumere

Abstract

People with psychosis commonly have poorer social networks and social support than the general population. However, qualitative social network features (e.g. presence of a confidant, perceived social support) are under-researched in first episode psychosis. Also, mechanisms through which poor relationships and support make symptoms and functioning in psychosis worse are largely unknown. This study aimed to investigate social network features and perceived social support in people with first episode psychosis, and also examined if the association between loneliness and paranoia was mediated by anxiety.

Thirty eight people with first episode psychosis were recruited for a cross-sectional study. The study used questionnaire and interview measures to assess symptoms, functioning and availability of and satisfaction with perceived social support. Additionally, qualitative social network features (loneliness, and presence of a confidant) were measured. A mood-induction task involved watching anxiety-inducing pictures and neutral / happy pictures on a computer screen. Visual analogue scales assessed changes in paranoia, anxiety and loneliness. A mediation analysis then tested whether anxiety mediated between loneliness and paranoia.

Results indicated that poor perceived social support, loneliness and the absence of a confidant were strongly associated with psychosis and depressive symptoms. The mediation analysis revealed that anxiety may be one potential mediator between loneliness and paranoia. Exploratory regression analyses further revealed that participants without a confidant were more likely to feel lonely when triggered into anxiety than those with a confidant. Finally, participants had temporarily raised paranoia when triggered into anxiety, and those with higher current negative symptoms felt more paranoid after anxiety-induction thus providing tentative experimental evidence for recent cognitive models of psychosis.

In line with previous studies, results showed that poor perceived social support, loneliness and the absence of a confidant were associated with more symptoms and poorer functioning. First episode patients appear to be more susceptible to feeling lonely when anxious. Anxiety may be one pathway through which loneliness affects paranoia. Potential clinical implications are discussed.

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*”Ein Freund, ein guter Freund, das ist das
Schönste was es gibt auf der Welt”*

*(A friend, a good friend, that’s the most
amazing thing that there is in the world)*

Comedian Harmonists

1. Literature review

1.1 Introduction and Overview

The paramount importance of social relationships for health has long been recognised (e.g. Cohen & Wills, 1985; Thoits, 2011). Those with good social relationships and social support are physically and mentally healthier and live longer (Holt-Lunstad, Birmingham, & Jones, 2008). Conversely, those with dysfunctional social networks and low social support have poorer physical and mental health, and poorer treatment outcome than those with functioning social networks and good social support (Greenblatt, Becerra et al. 1982).

People with severe mental health problems such as psychosis commonly struggle to develop and maintain functioning relationships and tend to miss out on good social support (e.g. Norman et al., 2005). It is a well established finding that social networks of people with psychosis differ from people without mental health problems. In comparison to the general population, people with psychosis commonly have fewer and poorer social relationships and support than those without psychosis (e.g. Angell and Test 2002). Social network disruptions and poor social support go along with poor quality of life and subjective well-being (Becker, Thornicroft et al. 1997; Bengtsson-Tops and Hansson 2001) and predict worse short-term clinical and occupational outcome in people with psychosis (Brugha, Wing et al. 1993). Conversely, patients with good social support and contact with close and other friends have fewer symptoms, better functioning and overall outcomes (Jablensky et al., 1992; Forrester-Jones et al., 2011). Since the majority of research into relationships and social support in psychosis has been undertaken with long term psychosis samples, it is less clear whether the picture is similar in people with first episode psychosis. It is conceivable that people at an early stage of their illness have equally good relationships and support than those without psychosis and only later during the course of

their illness lose their friends (as a consequence of the illness). On the other hand, poor relationships may predate the onset of psychosis thereby serving as a contributing or causal factor to the illness. Also, surprisingly little is known about the mechanisms through which poor relationships and poor perceived social support might make symptoms worse.

This thesis examines aspects of social relationships and support in first episode psychosis. The thesis aims to extend the current literature by experimentally studying one potential mechanism (anxiety) that may mediate the link between one social network characteristic (loneliness) and one psychosis symptom (paranoia). To achieve these aims the study draws on a sample of first episode patients combining interview and questionnaire measures with an experimental mood induction task.

This introductory chapter presents an overview of the relevant theoretical and empirical background to the examinations described in this thesis. First, this chapter briefly defines the concepts under investigation (social networks and social support), and briefly describes psychosis, its epidemiology and our current understanding of it. Next, the literature on social networks and social support in psychosis is reviewed. Afterwards, a short review summarises findings of mechanisms thought to link social networks and social support with psychosis symptoms. The chapter concludes with the aims and hypotheses of this thesis.

Schizophrenia and Psychosis – Epidemiology, conceptualisation and current understanding

Schizophrenia and related psychotic disorders are among the most severe psychiatric disorders (Mueser & McGurk, 2004), comprising a broad range of symptoms, including delusions, hallucinations, and thinking problems. The condition is highly debilitating, disrupts the individuals social and occupational functioning (e.g. Rössler, Joachim Salize, Van Os, & Riecher-Rössler, 2005), and creates immense burden for the patient, carers, services and society at large (Kuipers et al., 2006).

Diagnosis. A formal DSM-IV diagnosis of schizophrenia requires at least one positive symptom to be present (e.g. thought disorder, hallucination, delusions); continuous signs of disturbance for at least 6 months, and deteriorating functioning in areas of work or interpersonal relations (APA, 1994).

In this thesis and the reviewed literature, the term schizophrenia is used interchangeably with the term ‘psychosis’. Psychosis is a generic word and is commonly used to describe positive symptoms (hallucinations, delusions, thought disorder). The debate in the literature about the appropriateness and usefulness of the concept of schizophrenia (R. Bentall, 2006) is ongoing.

Epidemiology and comorbidity of schizophrenia. Estimates for lifetime risk fall within 0.12 and 1.6 % (Jablensky, 1997; Mueser & McGurk, 2004), and onset tends to be in early adulthood (15-39; Stefan et al., 2002). Co-morbidity rates are high and involve a broad range of conditions such as substance abuse, especially in recent onset patients (e.g. Green et al., 2004), depression and anxiety (Freeman & Garety, 2003), high mortality rates, suicide, and chronic medical disorders (e.g. HIV, diabetes; Auquier, Lançon, Rouillon, Lader, & Holmes, 2006). Both genetic and environmental factors account for the aetiology of schizophrenia (Mueser & McGurk, 2004).

Grouping of symptoms and first episode psychosis. Symptoms are typically classified into positive and negative symptoms. Positive symptoms involve hallucinations and delusions; they are described as positive because it is their presence as compared to ‘normal’ functioning that is conspicuous. Negative symptoms are characterised by a loss of experiences or behaviours and include impairments in affective experiences and expressions (e.g. poverty of speech, apathy, reduced motivation). A third sub-grouping ‘disorganised thinking and behaviour’ refers to word-salad, neologism, or incongruous affect.

Early psychosis. Psychosis is also classified into “early” and “chronic”. Early psychosis refers to those who are experiencing their first or second episode, or had their initial episode within the last 2-3 years (Baldwin et al., 2005). The first few years after illness onset have been found to be critical for treatment response and outcome (e.g. Birchwood et al., 1997) with rates of suicide, trauma and anxiety being elevated during this period (e.g. Birchwood et al., 2003). Particularly important for long-term outcome is the duration of untreated psychosis (DUP); the more time elapses from onset till treatment, the poorer the outcome (e.g. Addington, van Mastrigt, & Addington, 2003).

Current conceptualisations. Recent research has moved away from the categorical model of schizophrenia towards a dimensional model. Evidence shows that symptoms (e.g. hearing voices or paranoia) fall on a continuum of severity within the general population (R. P. Bentall, Claridge, & Slade, 1989; Freeman et al., 2005). Differences between patients and non-patients are quantitative rather than qualitative (Kuipers et al., 2006), with the reactions to the unusual experiences such as distress differentiating between clinical and non-clinical groups. Therefore, recent psychological research has focused both on individual symptoms, such as paranoia (Freeman et al., 2005) or auditory hallucinations (Trower et al., 2004), and on dimensions of individual symptoms, such as distress, conviction and pre-occupation rather than schizophrenia as a whole category.

1.2 Social networks and social support

Over the past four decades, researchers have attempted to define, describe and isolate quantitative and qualitative characteristics of social networks and social support that appear to protect and support both physical and mental health.

Social networks

There are several definitions of social networks in the literature. Early definitions come from the fields of anthropology and psychology. For example, Bott (1957) suggested that social networks are “all or some of the social units (individuals or groups) with whom a particular individual or group is in contact”. Speck and Attneave (1973) described social networks as all human relationships which have an enduring effect on the life of the individual. Greenblat et al. (1982) restricted this definition to family members, neighbours and friends to which most of us are connected through life, and according to Caplan (1974), social networks are an enduring pattern of social ties that play an important role in the maintenance of the psychological and physical integrity of a person. Wasyslenski et al. (1992) simply described the term as the number of social relationships we have and how these are arranged. Cresswell and colleagues (1992) discriminated between primary relationships (i.e. with those who we primarily interact with and have commitments with, e.g. friends and family) which usually provide social support and secondary relationships which are formal, less personal and less supportive (e.g. health professionals).

Social networks can be described in terms of structural and functional aspects. Structural aspects describe the existence and pattern of interconnections of network members rather than the content or quality of relationships (Hammer, 1981). Social networks are described in terms of both quantitative and qualitative aspects. Quantitative aspects refer to network size, density, and kin versus non-kin composition, marital status and living alone (vs. living with others). Qualitative aspects refer to the individual's degree of satisfaction with their social relationships. These include reciprocity (extent to which the relationship is characterised by giving as well as receiving), accessibility (extent to which network members can be contacted), multiplexity (number of separate functions provided by relationship), social isolation (pervasive lack of social contact or communication, presence or absence of a confidant, Lundgard, 2007)¹, and loneliness².

¹ A confidant is a person who provides and shares a confiding relationship with someone (also see page 18).

² Loneliness has been defined as a discrepancy between the actual relationships one perceives to have and the relationships one desires (Peplau & Perlman, 1982) (also see page 17).

Functional aspects refer to the functions provided by or perceived to be available from social relationships. These primarily include the different types of received and perceived social support.

Social support

The concept of social support is somewhat more diffuse than that of social networks (Cresswell, Kuipers, & Power, 1992). Syrotuik and D'Arch (1984) defined social support as "the degree to which an individual's social needs are satisfied through interactions with others" (pp. 229). In a similar vein, Cobb (1976) defined social support as the belief or perception that one is being cared for, loved, valued and belongs to a network of communication and mutual obligation. Hence, social support becomes available in the context of a social network. More precisely, social support can be conceptualised as the functional aspects of social relationships. The most frequently mentioned functions of supportive behaviours are emotional, informational instrumental support (Alloway, Bebbington, & others, 1987; Thoits, 2011). Social support is a complex construct consisting of several sub-constructs (Heller & Swindle, 1983; Vaux, Riedel, & Stewart, 1987). The most commonly distinguished constructs are *received* and *perceived* support. *Received* social support refers to the provision of supportive behaviours by others; whereas *perceived* social support refers to the recipients' perception of the general availability of support and their satisfaction with it (Sarason & Sarason, 2009). The main difference between both constructs is that *perceived* social support refers to anticipating help in times of need; whereas *received* social support refers to recalling previously received support in a given time period (Ibarra-Rovillard & Kuiper, 2011). The distinction is important, because research consistently showed that *perceived* social support is more consistently and stronger linked with health than *received* social support (Ibarra-Rovillard & Kuiper, 2011).

Thus the implication of the various definitions of social support is that people who perceive to be socially supported are healthier and better functioning than those with low perceived social support (Cohen & Wills, 1985; Thoits, 1986). However, despite these advances in understanding the construct of social support, there is much debate in the literature about how best to define social support and its construct validity (Sarason & Sarason, 2009). Not all social relationships are supportive or perceived as supportive; and others may even be abusive (Parry, 1988). Indeed, social relationships can be a source of stress and strain. Hence, social withdrawal may be protective in that it insulates an

individual from stressful relationships (Wing 1978; Kawachi and Berkman 2001).

However, it might still feel distressing and lonely to have no social support, even if this is a clients' preference (Duberstein et al., 2004).

This thesis investigates both structural and functional aspects of social networks and their importance for symptoms and functioning in people with first episode psychosis. The following section reviews the literature on social networks and social support in people with psychosis, starting with early studies that primarily focused on structural aspects of social networks, followed by a review of more recent studies, incorporating functional aspects of social networks with a focus on perceived social support, loneliness and the absence or presence of a confidant.

1.3 Social networks and social support in psychosis

Early studies: from the 70s to the 90s

Early studies of social networks in severe mental health populations primarily focused on structural aspects of networks. A series of studies in the 70s and 80s consistently showed that the network size of patients with chronic schizophrenia was substantially smaller than that of those individuals without mental health problems. The average network size of healthy participants consisted of 14 to 40 persons seen regularly by them, of whom 6-10 were intimately known (Cresswell et al., 1992) as compared to an average size of only 4-5 people (Segal & Holschuh, 1991) regularly seen by patients, with most of them being family members (Pattison et al., 1975; Cresswell et al., 1992). While other clinical groups also have smaller than average social networks, typically these are larger than for people with psychosis. For example, individuals with substance abuse difficulties were found to have a mean social network of 18.4 (Favazza and Thompson 1984), people suffering from depression have an average number of 5-10 (Pattison et al., 1975). Pattison et al. (1975) compared primary social networks of people with psychosis, neurosis, and healthy urban controls. They found that, in comparison to healthy people and those with neurosis, people with psychosis had a very small social network (4-5 persons) mostly consisting of family members, who were highly interconnected and had non-reciprocal interpersonal relationships with the patients. These findings were replicated by Tolsdorf (1976), who compared social networks of 10 people with schizophrenia with the social networks of a matched control-sample. Patients had smaller social networks and showed fewer multiplex relationships and had more dependent relationships than controls. Another study by Cohen

and Sokolovsky (1978) corroborated and extended these findings. They examined the relevance of clinical phenomena in contracting social networks of patients. Studying discharged patients with schizophrenia who were living in a Manhattan single occupancy hotel, they found that patients with schizophrenia had fewer social relationships than healthy controls. They also compared patients who had chronic and residual symptoms with patients without. Chronic patients with residual symptoms had fewer social ties, showed more dependent behaviour, undertook fewer instrumental activities and had more single-purpose ties than patients without residual symptoms.

Social networks, social support and outcome

A different series of studies examined the association between social networks and / or social support with outcome variables in severely mentally ill patients (M. Albert, Becker, Mccrone, & Thornicroft, 1998). In an early study, Lo and Lo (1977) used a sample of 133 schizophrenia patients and followed them up over 10 years, showing that the presence of a supportive relative at baseline predicted good outcome. These findings were corroborated by Strauss and Carpenter (1977) who followed-up 131 patients after five years, and found that more social support at baseline predicted fewer days in hospital, and more useful employment at follow-up. Cohen and Sokolovsky (1978) also examined the link between social networks and outcome, and found that small network size predicted rehospitalisation and psychopathology.

To extend these studies, and learn more about the time point at which social relationships break down, Lipton, Cohen, Fischer and Katz (1981) compared 15 first-admission patients with an age-matched group of 15 multiple-admission patients. The authors found that first admission patients had significantly larger social networks which were more strongly interconnected than those with multiple admissions. O'Connell, Mayo, Eng, Jones, and Gabel (1985) replicated these findings in a prospective sample of 60 patients with bipolar affective disorder. Further support comes from Faccincani and colleagues (1990) who interviewed 41 schizophrenia patients living in the community. They found that patients who received greater levels of social support showed improved social functioning, had fewer symptoms and made less use of in-patient facilities. Similarly, Holmes-Eber and Riger (1990) found, in a large sample of 310 schizophrenia patients with repeated hospital admissions and long-term stays, that they not only had fewer friends than those with fewer

admissions and shorter stays, but that their smaller networks were composed of more mental health and service professionals and acquaintances who they met in the services.

Drawing on a sample of 93 first-episode psychosis, Cole, Leavey, King, Johnson-Sabine and Hoar (1995) found that social support variables significantly predicted the care path³. Those who did not have a friend or family member were more likely to be admitted compulsorily. Furthermore, those who lived alone, had little social support, and were not involved with their GP, had an increased risk of compulsory admission by the police. The authors concluded that those with low social support had poorer outcome, including increased service-involvement. Becker and colleagues (1997) also found that larger social networks were associated with a lower likelihood of hospitalization. Interestingly, they also found that number of services used by patients grew proportionality with increase in social network size.

Findings on the role of social networks in mental health service utilisation were comprehensively reviewed by Albert et al. (1998) who concluded that smaller social networks or lower social support were associated with increased inpatient service use. Interestingly, enhanced support for carers was found to be associated with patients spending fewer days in hospital (Jed, 1989). They also highlighted that a higher proportion of family members (as opposed to friends) in the social networks predicted an increased risk of hospitalisation (Holmes-Eber & Riger, 1990). Presence of family and friends was generally associated with better self-care and employment (Evert, Harvey, Trauer, & others, 2002). Other qualitative network features associated with increased service use were fewer instrumental interactions (where the patient is the supporter), more dependent interactions (where the patient is supported) and less multiplexity (Albert et al., 1998).

Recent studies from the 1990s until today

The above described studies indicate that disrupted social networks are associated with higher levels of psychosis symptomatology and negative social and occupational outcomes in people with psychosis. However, a number of methodological and theoretical shortcomings of these studies are noteworthy; these will be discussed, along with newer studies attempting to address them.

³ Defined as the persons and services involved before the individuals' first contact with psychiatric services (e.g. police, GP, church) (Cole et al., 1995).

First, the majority of these studies investigated associations of psychosis with quantitative *structural* network characteristics such as size, connectedness or directionality of relationships, rather than more qualitative and functional aspects such as perceived social support, satisfaction with relationships, or loneliness. This is important, because objective features of social networks are related but different to these more subjective aspects of social relationships. For example, someone with a large network may actually feel lonely, whereas someone with a very small network may not. Equally, perceived social support is not necessarily higher in greater social networks (Macdonald, Jackson, Hayes, Baglioni, & Madden, 1998). Angell and Test (2002) therefore suggested that different facets of the experience of social networks and social support of people with psychosis, should be measured simultaneously. Furthermore, while the literature on social support largely suggests that higher perceived social support is associated with better mental health (e.g. Thoits, 2011), only few studies examining the role of perceived social support in mental health specifically used samples of psychosis patients (e.g. Erickson, Beiser, & Iacono, 1998; R.M.G. Norman et al., 2005).

Second, the majority of previous studies compared diagnostic groups as opposed to continuous measures of symptoms such as paranoia or hallucinations. This is important since despite the relatively smaller mean size of social networks in people with psychosis as compared to non-psychotic people, size and other network characteristics vary greatly (Angell & Test, 2002). In fact, it is these inter-individual differences that appear to relate to illness course and outcome. Newer studies therefore used continuous measures of psychosis symptoms, rather than comparing schizophrenia patients with controls when studying effects of social networks and social support (e.g. Norman et al., 2005). Continuous measures are also more in line with newer dimensional models of psychosis (Van Os et al., 2010).

Most studies utilising continuous symptom measures, found that smaller social networks and other network disturbances (e.g. fewer reciprocal relationships) were predominantly associated with negative symptoms (Hamilton, Ponzoha et al. 1989; Macdonald, Jackson et al. 1998; Bengtsson-Tops and Hansson 2001; Sorgaard, Hansson et al. 2001; Thorup, Petersen et al. 2006). However, there is also evidence for a link of poor social network

functioning with both negative and positive symptoms (e.g. Bengtsson-Tops and Hansson, 2001).

One reason for these mixed findings may be to do with the design of these studies. As Angell and Test (2002) point out, most studies used either cross-sectional designs or predicted clinical outcome over a very lengthy time, thus making it difficult to control for confounding variables. This also means that causal conclusions regarding the role of social networks in psychosis symptoms cannot be inferred. Angell and Test (2002) set out to address some of these limitations. Using a prospective sample of 87 psychosis patients, they investigated how short-term change in positive symptoms (over 6 months) impacted on social functioning. They found that an increase in positive symptoms was strongly associated with negative qualitative social network outcomes such as loss of reciprocal relationships, lower satisfaction with social relationships and loneliness.

Furthermore, the majority of social network and social support studies used samples of chronic patients. However, it is conceivable that social network and social support of first episode patients differ from those of chronic patients. For example, social network and/or social support may be relatively unaffected at an early stage of the illness, and only start deteriorating during illness course because either friends find it too challenging to persist with the friendship or because patients withdraw from their contacts (Brand, Harrop, & Ellett, 2011). Understanding the role of social networks and social support in early onset patients is important as it can have implications for early intervention service initiatives (e.g. mobilising social resources to protect further illness exacerbation).

One of the first studies with first episode psychosis patients was carried out by Erickson and colleagues (1998; 1989). Examining social support prospectively in first onset patients, they found that higher support by nonfamily members at time of treatment start predicted better functioning at 18 months follow-up (1989). Subsequently, Erickson et al. (1998) found that perceived social support from nonfamily members predicted adaptive functioning at 5 year follow-up, but perceived social support from family members did not. In the same year, MacDonald (1998) examined coping with stress in a sample of 55 first episode patients and 22 controls, and found that self-efficacy and perceived social support predicted more effective coping with daily stressors.

MacDonalds et al's study (2000) compared social networks and perceived social support in 26 people with first episode psychosis and closely matched controls. No difference was found between levels of perceived social support. However patients had significantly smaller social networks with more family members and more service providers as members than controls. These results were extended in Norman and colleagues' (2005) longitudinal study. The authors assessed perceived social support of 113 first episode patients at time of treatment initiation, and positive and negative symptoms as well as number of hospital admissions at 3 year follow-up. Higher levels of perceived social support predicted lower levels of positive symptoms and fewer admissions. The predictive power of perceived social support for symptoms and admissions at follow-up was independent of other potential predictors (gender, age, premorbid adjustment) thus lending further support for the unique contribution of perceived social support for symptoms and functioning. Subsequently, Hora, Subotnik, Snyder, and Nuechterlein (2006) interviewed 89 first onset patients at admission and retrospectively in the 12 months prior to hospitalisation. In a 15 month follow-up of a sub-group of 34 patients, results suggested that smaller social networks were associated with poor current and premorbid social and clinical functioning. They concluded that social network disturbances seem to exist by the time of first hospitalisation. These results were recently extended by Pruessner et al. (2011) who studied stress and psychosocial factors in individuals with an ultra-high risk of developing psychosis, first episode patients and healthy controls. Both at-risk individuals and first episode patients had lower perceived social support and active coping than controls, thus further substantiating the notion that poor social networks and poor social support are already present at illness onset. Furthermore, using prospective data from their treatment trial with first episode patients, Thorup et al. (2006) found small network size to be associated with longer duration of untreated psychosis, poor premorbid functioning, male gender and severe negative symptoms. Albert et al. (2011) replicated these findings in a cohort of 255 first episode patients and reported that stable social life predicted good outcome over a 5 year period.

Loneliness in Psychosis

Loneliness is a qualitative social network aspect and has been described as a distressing negative experience resulting from the discrepancy between the social relationships one wishes to have and those one actually perceives oneself to have (Peplau & Perlman, 1982). According to Young (1982), loneliness describes the absence or perceived absence of

satisfying relationships. Loneliness has both an affective character (unpleasant experience), as well as a cognitive element (perception of inadequate relationships; Heinrich & Gullone, 2006). Heinrich and Gullone (2006) highlighted that while loneliness is influenced by quantitative and objective aspects of social networks (e.g. size of social network, frequency of contact), it is influenced more by subjective appraisals of the social relationships, such as satisfaction and perceived adequacy (see also Asher & Paquette, 2003). Importantly, loneliness does not equate with objective social isolation, and, as noted earlier, someone with a large network may feel lonely, whereas someone with a very small network may not (Fischer, 1982). Equally, the total number of friends is not a good predictor of how lonely someone feels (Jones, 1982).

Research showed that loneliness is (a) associated with lower life satisfaction (Schumaker, Shea, Monfries, & Groth-Marnat, 1993), (b) psychosocial problems (e.g. low self-esteem, poorer social competence) (Heinrich and Gullone, 2006), and (c) mental health difficulties such as anxiety (Mijuskovic, 1986) or schizophrenia (DeNiro, 1995; Neeleman & Power, 1994). In addition, loneliness is associated with a variety of negative affective states such as shyness, boredom or feelings of alienation (Peplau & Perlman, 1982; Russell, Peplau, & Cutrona, 1980). Although loneliness has been described as a fundamental problem in psychosis (Fromm-Reichmann, 1959), it is surprising that only very few studies have specifically investigated it. One exception is a study by Neelman and Power (1994). They examined social support and depression in depressed, psychotic, and parasuicidal patients and controls. Psychosis patients had the smallest social networks, and felt lonelier than all other groups. Loneliness appeared to be independent of network size, lending further support to the notion that objective social isolation can be very different from loneliness. Interestingly, psychosis patients also reported not wishing to have more social support despite feeling lonely. DeNiro (1995) carried out retrospective interviews with 20 individuals with chronic schizophrenia. She found an increase of alienation, social isolation, and loneliness over the patient's lifetime, and conversely, a decline in positive connections with others. More research is warranted to further understand the role of loneliness in psychosis.

Another, arguably more important qualitative network feature is the *presence or absence of a confidant*. A confidant is someone who provides and shares a confiding relationship with another person. Characteristics of a confidant relationship are emotional intensity,

reciprocity and availability. The presence or absence of a confidant is strongly linked to the experience of loneliness (Green et al., 2001). In particular, having a confidant has been found to be protective against loneliness, and conversely, its absence is likely to increase feelings of loneliness (Green et al., 2001). Most studies assessing the importance of a confidant for mental health were studied within the context of depression. For example, Miller and Ingham (1976) showed that women who did not have anyone to confide in had more severe symptoms than those women who had a confidant. Equally, Brown and Harris (1978) reported that women who had a confidant (spouse, partner or close friend) were much less likely to develop depression after negative life events than those without. Lowenthal and Haven (1968) also showed that the presence of a confiding relationship was an important determinant of quality of life in the elderly.

Only very few studies to date examined the role of confidants in psychosis. In a recent study of older adults with schizophrenia and depression, Diwan and colleagues (2007) found that fewer confidants related to more depression. In a community study of severely mentally ill patients living in the South London area, Becker et al. (1997) found that besides number of friends and active contacts, confiding relationships were significantly associated with good quality of life.

The first aim of this project is to replicate findings of social networks and social support in first episode psychosis patients, and to extend the literature by addressing some of the outlined methodological limitations and shortcomings of previous studies. More specifically, this project aims to study qualitative and functional aspects of social networks in first episode psychosis, with a particular focus on perceived social support, loneliness and the presence or absence of a confidant.

1.4 Mechanisms of change in social networks and social support

Although the causal effect of poor social networks and poor social support (or its perception) on physical and mental health is well established, we still have limited understanding of the mechanisms through which poor social networks and support affect mental health. The following section first reviews attempts in the literature to elucidate pathways between social network and/or social support with mental health and then

outlines one potential mediator more specific to psychosis. The focus of this review is on psychological rather than physiological mechanisms⁴.

To date, very few researchers have attempted to systematically elucidate pathways between social network and/or social support with mental health. One of the first were Cohen and Wills (1985) who differentiated between *main effects* of social support on health, and *stress-buffering effects (indirect effects)*. Stress buffering occurs when social support (“buffers”) protects people from the negative effects of stress⁵ (Lakey & Orehek, 2011) by facilitating coping. The general notion is that stress-buffering effects occur either by strengthening protective factors and/or reducing the negative impact of life stress on well-being (Ibarra-Rovillard & Kuiper, 2011). Buffering is indicated, if associations of stressors with poor health are stronger in people with low social support compared to those with high social support. Cohen and Wills (1985) suggested that stress buffering only occurs in the presence of stress, whereas in its absence, social support is not linked to mental health, i.e. social support is conceptualised as providing help in times of need (e.g. stressful life events or circumstances). Conversely, social ties and support are thought to exert direct beneficial *main effects*, regardless of the persons’ stress experiences. In this sense, *main effects* are indicated if people with high social support are healthier than those with low social support, independently of stress.

Cohen and Wills (1985) illustrated these two different effects in the *main effect model* and the *stress-buffering model* (see Figure 1).

⁴ Following Thoits (2011), it is recognised that neuroendocrine, immune and cardiovascular mechanisms may also represent pathways through which social support may link to health. It is assumed that physiological responses can be influenced by psychological processes (Uchino, 2004, Thoits, 2011). For a review of physiological mediators of health, the reader is referred to comprehensive reviews by others (e.g. Uchino et al., 2006; Seeman & McEwen, 1996). The neuroendocrine pathway is also recognised in Cohen and Will’s main effect model (see Figure 1).

⁵ Stressful life events or stressful circumstances are defined as undesirable conditions that disrupt usual activities requiring readjustments (behaviourally, cognitively, emotionally) (Thoits, 1996). Stressors include negative life events such as bereavement, job loss or serious illness, as well as chronic stressors which continually interfere with daily tasks and role-oriented activities (Pearlin, 1983) such as chronic physical and mental illnesses. In that sense, onset of psychosis can be understood as a major negative life event, and its illness course as chronic and persistent stress. Mueller (1980) points out many life events concern changes to social networks, e.g. death of a loved one, or divorce, thereby inevitably affecting social support.

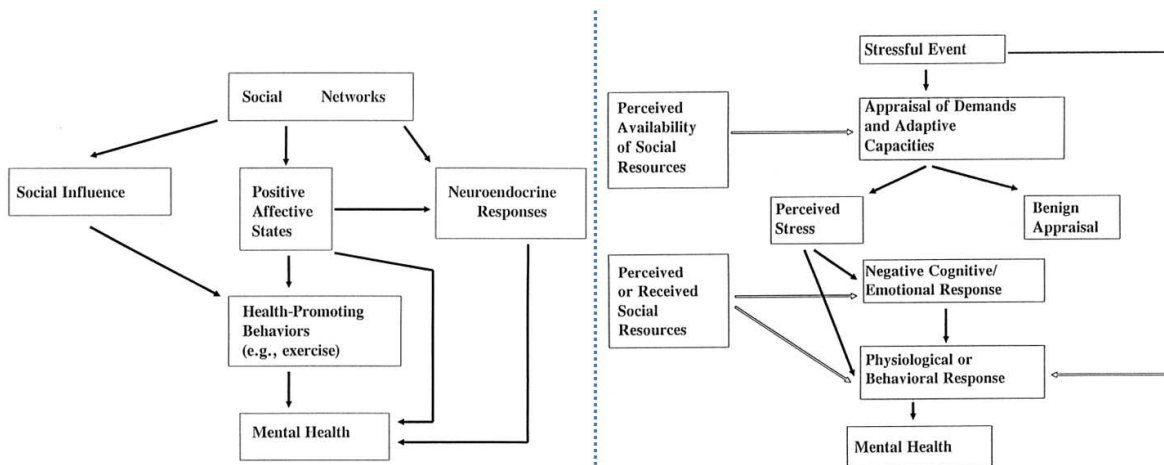


Figure 1-1 Main effect model (left) and stress-buffering model (right) according to Cohen and Mills (1985), adapted from Kawachi and Berkman (2001)

Both models make different predictions about the pathways through which social networks and social support are supposed to exert their protective influence. The main effect model describes several pathways of how participation in a social network can *directly* influence health. One direct way is adherence to health-relevant behaviours that are promoted in the social network such as non-smoking or physical activities. Furthermore, being part of a social network may also directly produce positive psychological states such as sense of belongingness, worth or security which in turn may enhance mental health via improved mood and self-esteem. On the other hand, the stress-buffering model specifies more *indirect* effects of the social network on the person's well-being. More specifically, social support received from social network members is thought to *buffer* (i.e. *modulate*) responses to stressors at various stages between the stressful event and mental illness. They proposed that social support buffers stress by primarily affecting appraisals and coping. For example, the authors speculated that *perceived availability* of social support may lead to more benign appraisals of the situation, thereby preventing subsequent negative emotional and behavioural responses. They also suggested that *perceived (or received)* social support may either reduce negative reactions to stressors or dampen physiological/behavioural responses to stress. On the other hand, low *perceived (or received)* social support is supposed to lead to negative appraisals of the situation and consequently impact adversely on mental health.

Both models are complimentary in that they describe different processes through which social network / social support may affect mental health. Empirical support for both models was limited at the time of their publication, and mainly came from correlational

studies showing that *perceived availability* of social support mostly acted as a stress buffer, whereas *integration* in a social network generally seemed to act independently of stress levels (see reviews by Cohen and Wills 1985).

Critique of stress buffering

While stress-buffering theory proposes that social support only has *indirect* beneficial effects in the presence of stress, more recent research suggests *direct* effects of social support on physical and mental health, especially via perceived emotional support, even in the absence of stress (e.g. Thoits, 2011 for a review, Turner & Lloyd, 1999). In their extensive review of social support studies in depression, Lakey and Cronin (2008) showed that almost all studies, except Brown and Harris's original study (1978), found main effects of social support on depression, and no stress-buffering. Similarly, Wade and colleagues (2000) found no supportive data for stress-buffering. Lakey and Orehek (2011) highlighted a number of other shortcomings of stress-buffering theory. For example, the amount of received social support cannot explain the link between perceived social support and mental health. Stress buffering theory assumes that perceived social support is a veridical account of received social support, i.e. perception of social support should stem from actual provision of support (Lakey and Orehek, 2011). However, received and perceived social support are not, or only weakly correlated (Lakey and Orehek, 2011). Furthermore, received social support has no or inconsistent effects on health; while effects of perceived social support are stronger for health and more consistent (Bolger & Amarel, 2007; Thoits, 2011; Uchino, 2004, 2006).

In addition, stress-buffering theory's proposal that coping and appraisal account for the link between perceived social support and mental health is largely unsubstantiated (Lakey & Cohen, 2000; Lakey & Orehek, 2011). However, a recent large epidemiological study found some evidence that high perceived social support had stress buffering effects, in that the adverse impact of stressful life events on mental health was lower in people with high perceived social support (Moak & Agrawal, 2010).

The past few years have seen significant advancements in delineating pathways between social network / social support and mental health. These will be briefly presented, followed by a discussion of possible pathways more specific to psychosis.

Relational Regulation Theory

Relational Regulation Theory (RRT) was recently put forward by Lakey and Orehek (2011) to explain the well-established main effects between perceived social support and mental health which cannot be accounted for by stress-buffering theory. RRT builds on attachment research and capitalises on the idea that human interactions elicit affect, action and thought. More specifically RRT explains that “main effects of social support on mental health occur when people regulate their affect, thought and action through ordinary yet affectively consequential conversations and shared activities, rather than through conversations about how to cope with stress” (pp. 482). According to RRT “perceived support typically does not directly cause affect but emerges from the types of social interaction that successfully regulate affect” (pp. 490). For example, a distressed person speaking to her friend about her divorce may feel more hopeful after the conversation not because of concrete coping tips received, but because of a positive affect (e.g. sense of belongingness) resulting from relating to this particular person. Furthermore, regulation is thought to be reciprocal because the help provided also influences the affect, thoughts and behaviours of the provider, which in turn impacts the receiver. In the example of the distressed person interacting with her friend, it is plausible to assume that the helper feels relieved if he sees that the recipient is soothed by the interaction which in turn may be perceived by the recipient who is then further comforted.

RRT operationalises relationships in quantitative terms. This allows a clear distinction to be made between relationships and recipients’ personality. This is important, as personality differences between recipients confound the link between social support and health (Lakey and Orehek, 2011). In other words, dispositionally unhappy people might be unhappy about everything, including their support providers. For a detailed account of RRT’s theoretical background, how the theory quantifies relationships, and its principles, the reader is referred to the original article by Lakey and Orehek (2011).

In a recent theoretical paper Thoits (2011) identified 7 social psychological mechanisms through which social ties and support may affect mental health. These are presented in Table 1.1.

Table 1-1 Proposed social psychological mechanisms through which social support may promote health (Thoits, 2011)

Mechanism	Description
Social influence / social comparison	Normative and behavioural guidance through comparison with others (e.g. appropriateness of smoking)
Social control	More active and direct effects, primarily through effects on health behaviour. Network members monitor, reprimand, promote adherence to health behaviours (e.g. poor sleep, diet may be picked up by the social network with an attempt to influence)
Behavioural guidance, purpose, and meaning (mattering)	Implicit form of social control; relationships come with normative rights and duties, and supply behavioural guidance and meaning (“knowing who we are to others also provides purpose and meaning in life”, Thoits, 2011, pp. 148).
Self-esteem	Self-evaluations with reference to others affect self-esteem which in turn affects mental health.
Sense of control or mastery	Accomplishing role related tasks (e.g. earning salary, being sociable, etc) increases sense of mastery which enhances mental health (e.g. Taylor & Stanton, 2007).
Belonging and companionship	Connections with others are a source of <i>sense of belonging / companionship</i> which increases positive affect thereby improving health (e.g. Uchino, 2004). Conversely, loneliness (lack of companionship) leads to poor mental health (e.g. Cacioppo et al, 2002).
Perceived social support	Social networks can provide emotional, informational and instrumental support.

These proposed mechanisms have not been systematically tested yet; nevertheless Thoits (2011) speculated that they are likely to be correlated with each other given their common origin in social relationships. Thoits (2011) emphasised that further research is indicated to

clarify to what extent these mechanisms are independent constructs, and assess their relative and independent contribution to subsequent health.

Social support as 'Emotional sustenance' and 'Active coping assistance'

Thoits (1996; 2011) proposed that there are two broad types of social support, *emotional sustenance* and *active coping assistance*. *Emotional sustenance* refers to demonstration of caring, valuing and understanding and is likely to influence the individual's health *indirectly* through the above described mechanisms (see Table 1.1). *Active coping assistance* refers to direct help provided by supporters to help recipients to implement coping strategies. For example, a helper can remove a distressed individual from the stressful situation or offer advice on how to change it, distract him/ her (behavioural problem-focused), or may help to reinterpret the situation in more benign ways (cognitive problem-focused). Thoits (2011) further proposed that there are two broad categories of people providing those supportive behaviours: significant others (primary group) who usually do not have prior experience with the stressor (e.g. psychosis) and similar others (secondary group) who do have prior experience (e.g. acquaintances with the same illness). He argued that the effectiveness of support depends on both its source and type, i.e. not everyone can provide each type of support effectively. Thoits (2011) argued that significant others are likely to be the most effective people in providing emotional support by (a) valuing, listening, and caring, thereby sustaining the individual's sense of belongingness, and self-esteem, and by (b) instrumental support which may also reduce the burdens of the stressful situation, thus decreasing its perceived threat and impact. Conversely, similar others are thought to be in the best position to provide genuine empathic understanding⁶ and validation of the individual's concerns (emotional sustenance) because they have experienced similar stresses. Also, similar others' coping assistance, informed by their own experiences, is thought to directly protect physical and mental health and enhance individuals' sense of mastery (e.g. by reframing threat beliefs or providing information). Similar others also serve as effective role models thus influencing the recipients' sense of control.

⁶ Empathic understanding from similar others serves two functions to the distressed person: (1) it provides reassurance that emotional reactions are valid (Thoits, 1985), and (2) because similar others share the same feelings they are less likely to reject the person (Thoits, 1986).

Fulfillment of psychological needs

Another possible pathway through which support may relate to health has been recently put forth by Ibarra-Rovillard and Kuiper (2011). According to their model, positive or negative effects of social relationships on mental health depend on whether they are perceived as fulfilling or undermining basic psychological needs such as belongingness or autonomy (see Ryan & Deci, 2000). A wealth of research suggests that those needs can be either met or thwarted by others. The authors emphasise the importance of perception of the responsiveness of others rather than the actual provision of supportive behaviours. These processes link in with Thoits (2011) delineation of social psychological mechanisms (see Table 1.1) explaining pathways of support and health; and serve to explain the main effects of social support. Furthermore, their model also incorporates a pathway explaining stress-buffering which is thought to occur in the context of specific, circumstantial stressors.

Social relationships can serve several functions in times of stress (see above, e.g. emotional support, instrumental support, companionship). The authors noted that although those forms of help are primarily aimed at fulfilling circumstantial needs, they can also lead to fulfilment of basic psychological needs thus positively impacting on mental health. Importantly, the degree to which those forms of help are experienced as beneficial depends on the extent to which they are perceived as satisfying basic needs (e.g. based on the support, whether the person feels cared for and better able to cope with stress). Since it is the perception of whether needs are met, the model, yet again, strongly suggests that measures of *perceived* rather than *received* support are crucial.

Although Ibarra-Rovillard and Kuiper (2011) placed their model in the context of depression, it can be regarded as highly relevant for other disorders, especially given the high overlap between depression and other mental health difficulties such as psychosis. People with psychosis are likely to experience depressive symptoms at some point during the illness course (Buckley, Miller, Lehrer, & Castle, 2009). Cognitive models of psychosis also emphasise the affective changes as a key process in maintaining psychotic appraisals (Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001), and there is recent evidence for this using longitudinal analyses (Fowler et al., 2011).

Pathways of social networks and social support in psychosis

The above described models can be seen as important advancements in understanding the pathways through which social networks and social support may be helpful or harmful to mental health. However, they do not specifically address the link of social network and social support with symptoms or functioning in psychosis. The question remains: what are the exact mechanisms through which poor social network functioning such as social isolation or feelings of loneliness or low perceived social support make positive or negative symptoms worse and poor outcomes more likely? Cognitive models of positive symptoms emphasise the importance of factors responsible for the maintenance of psychotic appraisals (Bentall, Kinderman et al. 1994; Garety, Kuipers et al. 2001) such as biased reasoning processes, emotional processes, dysfunctional schemas and adverse social environments. Although Garety and colleagues (2001, see Figure 1.2) mentioned adverse social environments as one factor impacting negatively on psychotic appraisals, they do not specifically describe the pathway through which both are causally linked.

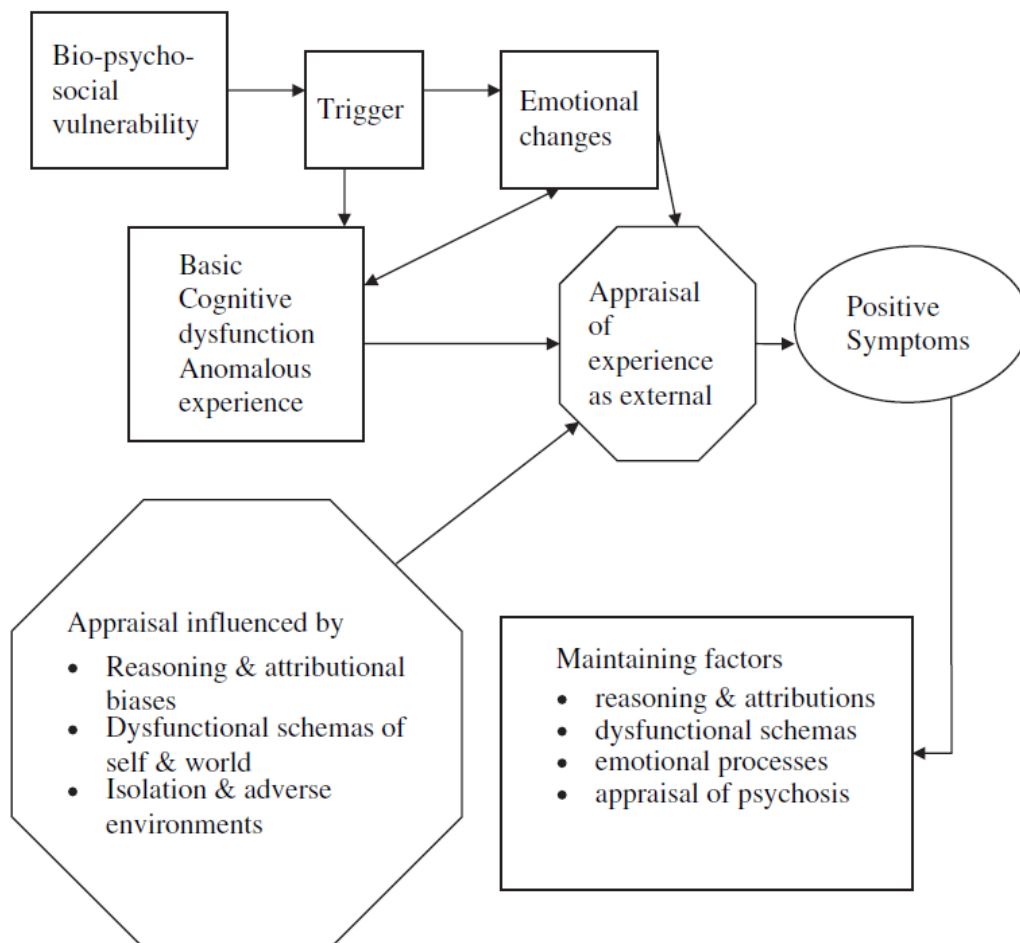


Figure 1-2 Garety et al.'s (2001) model of positive symptoms in psychosis as presented in Kuipers et al. (2006). The model makes specific reference to isolation and adverse environments as factors supposed to be influencing appraisals of the experiences as external.

Positive symptoms and loneliness

Loneliness is one poor qualitative social network aspect that often affects people with psychosis (DeNiro, 1995; Neelman & Power, 1994). To focus on positive symptoms in psychosis, a number of pathways between loneliness and symptoms such as distressing voices or unusual ideas are conceivable. For example, loneliness may directly increase anxiety and depression (see Heinrich & Gullone, 2006) which in turn may exacerbate psychotic symptoms (Freeman and Garety, 2003). Connections to other people provide a source of belongingness and companionship (Thoits, 2011), and it is conceivable that unfulfillment of these basic needs may cause depression or contribute to its development (Weeks, Michela, Peplau, & Bragg, 1980). Equally, perceiving oneself as socially excluded may directly trigger anxiety (Leary, 1990); however, the causal pathway between loneliness and anxiety is yet to be established (Cacioppo et al., 2002).

Despite the fact that loneliness, depression and anxiety have been described as distinct constructs (Anderson & Harvey, 1988) they are strongly linked and may further exacerbate each other (Mijuskovic, 1986; Uchino 2004; Heinrich & Gullone, 2006). Furthermore, it is conceivable that feelings of loneliness may distort thinking processes thus increasing anxiety symptoms. For example, everyday events have been found to elicit threat appraisals in lonely, but not in nonlonely people (Hawkley, Burleson, Berntson, & Cacioppo, 2003). Equally, anxiety may also trigger feelings of loneliness, as it is conceivable that anxious thinking styles may negatively distort the perception of one's own social support.

How does anxiety increase psychosis symptoms?

How does feeling anxious and / or depressed contribute to psychosis symptoms? Garety and colleagues (2001) emphasised the importance of affective processes in the formation and maintenance of symptoms. While others highlighted the importance of depression and hopelessness in the exacerbation of psychosis symptoms (Birchwood & Iqbal, 1998a), Garety and colleagues focused on anxiety. They proposed that anxiety drives a number of dysfunctional processes and behaviours which are thought to contribute to psychosis symptoms, such as selective attention (to experiences supporting psychotic beliefs and minimising disconfirmatory evidence), safety behaviours (preventing disconfirmation of beliefs), or meta-cognitive beliefs (e.g. uncontrollability of thoughts). Furthermore, anxiety has been found to produce threat anticipation and to trigger emotional reasoning, i.e. a search for meaning consistent with affect-associated beliefs (Freeman, 2007).

Other mechanisms that link loneliness with poor physical and mental health have been proposed. Loneliness may directly lead to poorer health practices such as alcohol or drug abuse (Caccioppo et al., 2002) thereby exacerbating psychosis symptoms (Drake et al., 1990). Furthermore, lonely people tend to have poorer sleep which may directly increase anxiety and psychosis symptoms (Morphy et al., 2007; Freeman and Freeman, 2008). Specifically, insomnia has found to exacerbate negative affect and induce altered perceptual states thereby increasing paranoia (Freeman et al., 2010; Freeman, Pugh, Vorontsova, & Southgate, 2009).

It is also conceivable that being isolated and feeling lonely makes it harder to think of alternatives to unusual ideas (Garety et al 2001). Or, it may be easier to attribute blame to others for unusual and distressing experiences when you are alone. It may also be a combination of all these factors that might explain how social network disturbances increase psychotic symptoms.

Clearly more research is indicated to further delineate such possible pathways, through which feelings of loneliness may contribute to psychosis symptoms.

Negative symptoms and poor social network and support characteristics

It may also be important to consider the relationship between negative symptoms and poor social network characteristics such as loneliness. Negative symptoms of psychosis such as affective flattening, alogia or avolition may directly disrupt the patient's network. Recent cognitive characterisations of negative symptoms (see Rector, Beck et al. 2005) suggested that a number of negative appraisals drive negative symptoms. Rector and colleagues (2005) proposed that the expression of negative symptoms depends on the intensification of negative beliefs about the self and others. For example, they suggested that patients often have negative beliefs about their performance in social, occupational and interpersonal contexts and therefore stay away from social and occupational situations. Furthermore, they proposed that delusional appraisals (e.g. "People are trying to kill me") lead to withdrawal from social contexts and thus to social isolation. Also, psychosis patients often hold stable negative attitudes towards social affiliation (e.g. "Having close friends is not as important as many say.", Rector et al., 2005, pp. 250) and as a consequence tend to withdraw from others. In addition, a number of negative expectancy appraisals are hypothesised to contribute to negative symptoms; these are 'low expectation

of pleasure' (e.g. "social events are no fun"), 'low expectation of success' (i.e. low self-efficacy, e.g. "I will fail"), 'low expectancies of acceptance' (e.g. "I look strange, people will reject me"), and 'perception of low psychological resources' (e.g. "I am incapable of expressing my feelings"). These appraisals are thought to drive disengagement from social contexts.

The other conceptualisation of negative symptoms in psychosis is that they are a way of avoiding stress, and may become safety behaviours which then prevent disconfirmation of unusual beliefs and maintain or exacerbate them (Freeman, Garety et al. 2007). More specifically, Freeman and colleagues (2007) built on the notion, first proposed by Hemsley (e.g. Hemsley, 2005), that negative symptoms can be a secondary consequence of positive symptoms (Carpenter Jr, Heinrichs, & Alphas, 1985) in that they may function as safety-behaviours. For example, they highlighted that avoidance of interpersonal situations (e.g. as a result of believing that others may do harm), may present as a loss of interest in activities (anhedonia-asociality) or as physical inactivity (avolition-apathy). They also suggested that means of withdrawal as a safety-behaviour may contribute to the formation of negative symptoms by understimulation (similar to the effects of institutionalisation).

To the best knowledge of the author, no study has yet investigated mechanisms linking aspects of social network and social support with psychosis. Therefore, the second aim of this project is to investigate one potential pathway (anxiety) between perceived loneliness and psychosis symptoms (paranoia).

1.5 Summary and aims of thesis

This chapter reviewed findings of social networks and social support in psychosis. The review conclusively showed that poor social network / social support are common in people with psychosis and linked with poor outcomes. Two main shortcomings of the literature have been highlighted. First, most studies investigating social network / social support in psychosis drew on samples of chronic patients. Therefore, it is unclear whether findings generalise to people with first episode psychosis. Second, despite the wealth of data supporting the association of poor social network / social support with poor mental health, surprisingly little is known about mechanisms linking the two. Although researchers have begun to suggest possible pathways explaining links between social network / social support and mental health, there is still a paucity of studies elucidating

possible cognitive emotional pathways, especially in the field of psychosis. Cognitive models of psychosis emphasise affective processes, in particular anxiety as one factor in the formation and perpetuation of psychotic appraisals. It was considered that anxiety might therefore be one potential pathway in psychosis that may link one poor qualitative network feature (loneliness) with one psychosis symptom (paranoia). The thesis sets out to begin to close this gap by investigating cognitive and emotional factors associated with social network features and perceived social support in first episode patients.

The following aims and hypotheses will be investigated:

(1) To examine cross-sectional relationships between social network characteristics and social support with positive symptoms, negative symptoms and functioning in a sample of recent onset psychosis patients.

Hypothesis 1: *Positive and negative symptoms of psychosis and overall functioning are related to qualitative aspects of social networks and poor perceived social support. Specifically, low perceived social support, poor perceived adequacy of social support, perceived loneliness and the absence of a confidant will be related to psychosis symptoms.*

(2) To investigate anxiety as a potential pathway between loneliness and psychosis symptoms.

Hypothesis 2: *Predicted associations between feeling lonely and feeling paranoid after anxiety-induction are significantly reduced when controlling for anxiety (mediation analysis).*

Exploratory Hypothesis 3: *Those participants with poor perceived social support are more easily induced by negative affect into perceived loneliness than those with high perceived support.*

To validate, in part, cognitive models of positive symptoms of psychosis (Garety et al., 2001; Kuipers et al., 2006).

Exploratory Hypothesis 4: *Those participants who are more easily triggered into anxiety have temporarily raised rates of subsequent paranoia. Furthermore, participants with high current psychosis symptoms are more easily triggered into feeling anxious and paranoid.*

2. Method

2.1 Participants and recruitment

The sample consisted of 38 individuals with a first episode in psychosis. In line with other studies, “first episode” was defined as illness onset within the last 5 years (e.g. Baldwin et al., 2005). Individuals were recruited from outpatient services and psychosis teams within the South London and Maudsley NHS Foundation Trust (SLaM).

This study collaborated with Dr. Craig Morgan’s psychosis research team who at the start of this project was running a large multi-centred trial attempting to recruit all first episode psychosis participants who presented within any of the SLaM services. The aims of this collaboration were (1) to facilitate recruitment and (2) to reduce duplication of collected data, and participant fatigue.

(1) Participants who had completed Dr. Craig Morgan’s study were asked whether they would be interested in taking part in some further research. If participants expressed an interest and provided consent, Dr. Morgan’s team passed on their contact details to the author of this study who then made arrangements to contact the participant. Participants were initially contacted by telephone and provided with details about the study.

Participants were then either booked in for an appointment or in case they asked for more information were sent the information sheet via email/mail and contacted again one week later.

(2) In order to avoid over-fatiguing and over-researching of participants by asking the same questions multiple times, some of the relevant participant information that had already been collected was provided by Dr. Morgan’s team (demographic information).

Furthermore, recruitment and testing of this sample was shared with Dr. Fergus Kane, a fellow DClinPsych trainee who was also recruiting first episode psychosis patients as a control group for his study (see procedure below). Two thirds of the sample were recruited and tested by the author of this study. The other third was recruited and tested by Dr. Fergus Kane.

Eligibility criteria:

- Presence of an untreated first episode of schizo-affective or non-affective psychosis (even if long-standing) (ICD-10: F20-29; F30-33, DSM equivalents: 295.xx to 298.xx) during the study period of Dr Morgan's study (1st of January 2010 to 30th April 2012).⁷
- Aged 18-64
- Sufficient comprehension of the English language
- Absence of a history of brain injury, a known organic cause to their psychosis or a primary diagnosis of drug or alcohol dependency
- First contact with severe mental health services within the last 5 years.

Demographic information of the sample is provided in Table 2.1.

⁷ [n.b. this does not mean that participants had to be untreated at the point at which they were initially assessed by Dr Morgans' team, only that treatment had not begun prior to 1st January 2010] Treatment had been broadly defined by Dr Morgan's team as
(1) contact with secondary mental health services for an episode of psychosis: i.e. the individual had a) been accepted as a referral by secondary mental health services and b) disclosed to the secondary mental health team symptoms that Dr Morgan's team considered psychotic, i.e. rated 2 or more on the SCAN.
(2) prescription of anti-psychotic medication for 1 month or more by a GP, prison doctor, of private psychiatrist in the absence of contact with or pending referral/transfer to secondary mental health services.

Table 2-1 Demographic and clinical characteristics of sample (N=38)

Variable	<i>N (%)</i>	<i>Mean (SD)</i>
Sex		
Male	23 (60.5%)	
Female	15 (39.5%)	
Age		32.26 (9.6) , [range 21-56]
Ethnic origin		
White	20 (52.6%)	
Black	13 (34.2%)	
Other	5 (13.3%)	
Years of education		14.5 (3.9)
English Language		
Native	32 (84.2%)	
Non-native	6 (15.8%)	
Duration of untreated psychosis (DUP)*	(N=36)	Median: 12 Mean: 135 (502) Min: 0, Max: 2652
CES-D		21.46 (12.9)

*DUP is defined here as time elapsed from onset of symptoms till beginning of treatment in weeks. The distribution of this sample was skewed because of two outliers with extremely long DUPs with onset of symptoms before the age of 16. Therefore, the Median is reported as it represents a more accurate measure of central tendency than the mean DUP. Data is missing for two participants.

2.2 Assessment of Symptoms

Psychosis symptoms and functioning were assessed using the following measures:

- *Scale for the Assessment of Positive Symptoms* (SANS, Andreasen, 1984a) (Appendix B1). The SANS is a widely used semi-structured interview to assess positive psychosis symptoms in the past month. The scale consists of 35 items and is divided into four subscales: hallucinations, delusions, bizarre behaviour, and formal thought disorder. Items are rated on 6-point scale from 0 (no abnormality) to 5 (severe). The SANS was carried out twice. First with regards to the participant's worst 2 week period during their first episode and second with regards to current

positive symptoms. Total scores and subscores of each symptom cluster were calculated.

- *Scale for the Assessment of Negative Symptoms (SANS, Andreasen, 1984b)* (Appendix B2). The SANS is a widely used semi-structured interview to assess negative symptoms of psychosis in the past month. It consists of 25 items which are divided into 5 subscales: affective flattening or blunting, alogia, apathy, asociality, and inattention. Items are rated on a 6-point scale from 0 (no abnormality) to 5 (severe). The SANS was carried out with regards to current symptoms. Total scores and subscores of each symptom cluster were calculated.
- *Time budget measure (TBM, Jolley et al., 2006)* (Appendix B3). The TBM is an indicator of social functioning. The measure takes the form of a diary over a week. It is completed from a structured interview during which the interviewer probes for activities and social contact over the specified week; usually the past week, but if that is not typical a more representative one is chosen. Each day of the specified week is divided into four sections (morning, middle of the day, afternoon and evening), and depending on the level of activity shown during each section, the interviewer assigns a score between 0 and 4 to each section according to the following key:
 - 0 - doing nothing, lying, thinking, sleeping, sitting
 - 1- Predominantly passive activity, e.g. watching TV, listening to the radio.
 - 2- An independent activity requiring some planning and motivation, but relatively simple or brief, e.g. a walk to the local shops to get cigarettes, tidying room, washing-up, preparing a simple meal for oneself.
 - 3 - Several 2-rated activities completely filling a time period, sounding busy or a more complex and demanding but unvaried activity, e.g. a visit involving public transport, or prolonged social contact with others.
 - 4 - Time period filled with a variety of demanding independent activities requiring significant motivation and planning and with some variation in tasks. E.g. work, a course of study, a trip out requiring organisation.

The overall Time budget score is the sum across all sections of all days. A previous pilot study (Jolley et al., 2005) has revealed high psychometric properties (interrater reliability: $r=.99$; test-retest reliability: $r=.83$) and good face validity.

- *Subjective Units of Distress, Mood, State Anxiety, State Symptoms and Loneliness* (Appendix B4). Six visual analogue scales assessed subjective units of (1) perceived loneliness, (2) subjective state anxiety, (3) general distress, (4) happiness, (5) state symptoms (paranoia), and (6) sadness, at four different points during the assessment: (1) baseline 1 (prior to the interviews), (2) baseline 2 (before picture presentation); (3) after exposure to the mildly anxiety inducing pictures; and (4) after exposure to the neutral / happy pictures. Participants indicated how they were feeling *right now* with regards to each of the items on a scale from 0-100 [anchors were: not at all, slightly, moderately, very, extremely].
- *Center for Epidemiologic Studies Depression Scale (CES-D)* (Appendix B5). The CES-D is a widely used 20-item self-report questionnaire to measure depressive symptomatology in adults (Radloff, 1977). The clinical cut-off is 16.

2.3 Assessment of Social Network and support variables

- *The Multidimensional Support Scale* (Winefield, Winefield, & Tiggemann, 1992) (Appendix B6). This self-report scale assesses *availability* of social support (e.g. listening, trying to understand, offering practical help) as well as *perceived adequacy and satisfaction* with the support provided. The scale measures *availability* and *adequacy* for three different groups: *confidants* (family and close friends), *peers* (e.g. others suffering the same illness, work colleagues, etc), and *experts* (those with an official role to provide specialist help for whatever challenge it is; here psychologist, psychiatrists and care team). *Availability* of support is calculated as the total frequency of supportive behaviours (never, sometimes, often, usually or always; scored 1-4), while *perceived adequacy* is operationalised as the participant's satisfaction with that frequency (would have liked more, would have liked less, it was just right; scored 1-3). This measure yields 6 subscale scores (availability and adequacy from each of the three sources), which can be combined in different ways if appropriate, e.g. looking at total adequacy of support across all sources, or comparing support received from one source with that from

another group. For reasons of brevity, we did not assess the subscale “peers” in this study, resulting in 4 subscores. Psychometric properties of the Multidimensional Support Scale are high, i.e. internal reliability has consistently been above .75 for both scales (Winefield et al, 1992, 1993) and moderate to high correlations with measures of psychological well-being have been revealed (Winefield et al., 1992, 1993). *Adequacy* has been found to be relatively independent of *availability* (Winefield et al, 1992), and it is usually the perceived *adequacy* of social support that significantly correlates with affective states such as depression (e.g. the more satisfied someone is with the support provided, the less they tend to be depressed, Winefield et al., 1992).

- *Loneliness*. This 1-item question (Appendix B6) asks individuals on how many days they felt lonely and in need of companionship in the past week. Similar single-item measures of loneliness were used in past studies (Rook, 1987).
- *Confidant*. This 1-item question (Appendix B6) asks individuals whether they have anyone to confide in (previously used successfully in psychosis studies, e.g. Onwumere et al., 2009).

2.4 Experimental mood induction picture task

This picture viewing task was designed for this study to induce mild levels of anxiety. Participants watched two picture sets: “Mild anxiety provoking pictures” and “Neutral / happy pictures” on a computer screen. The order of picture sets was counterbalanced, and alternated for each participant, i.e. the first participant watched anxiety pictures first, the second participant watched neutral / happy pictures first, and so forth. To avoid mood carry-over effects both picture sets were separated by a 5 minutes distraction phase during which participants completed a verbal fluency task (FAS). Pictures were mainly drawn from the International Affective Picture System⁸ (IAPS, Lang, Bradley, & Cuthbert, 1997) and partly downloaded from a widely used online database for pictures (www.gettyimages.com). Each picture set consisted of 15 pictures. Picture presentation was randomised, with each picture being presented for 6 seconds followed by a 1 second

⁸ The IAPS is a large set of standardised, emotionally-evocative, internationally-accessible, colour photographs that includes contents across a wide range of semantic categories.

interval. The experimental software PsychoPy (www.psychopy.org) was used to present pictures. A description of the pictures is provided in Appendix C1.

Participants were given the following instructions:

Dear participant,

Thank you very much for taking part in our study.

In the following you will see a series of pictures. You may find some of them unpleasant. Please watch the pictures closely and imagine that you are an observer present at the scene. Please do not fight any emotional response you may have to the pictures because we need to know what effect they have on you. You will be asked some questions about your mood at the end of the presentation.

Please keep looking at the monitor throughout the task.

If you have any questions, please do not hesitate to ask them now.

Pre-post changes in affect, distress, paranoia and loneliness were measured with the above described visual analogue scales that were filled out at the beginning of the assessment session (baseline 1), prior to the presentation of the pictures (baseline 2) and after each of the two picture sets. The reason for including two baseline measures is that we wanted to be able to control for both potential initial anxiety at the start of the session and for potential heightened affect after completion of the symptom measures.

The reason for using emotional pictures to induce affect was that pictures are a well established means for inducing mood (Herrmann, Ehrlis, & Fallgatter, 2003). Pictures from the IAPS have been widely and successfully used to induce emotional states such as anxiety, positive affect or sadness, in both healthy and clinical samples (e.g. Casada, Amdur, Larsen, & Liberzon, 1998; Meagher, Arnau, & Rhudy, 2001). Studies using samples of psychosis patients have shown that both patients and controls experience comparable amounts of pleasant, unpleasant, high, and low activation emotion in response to these pictures (Herbener, Song, Khine, & Sweeney, 2008; Quirk & Strauss, 2001; Volz, Hamm, Kirsch, & Rey, 2003).

2.5 Procedure

The study was approved by the local research ethics committee (South East London Research Ethics Committee, Ethics reference: 11/LO/0573). Individuals provided informed consent and were free to stop the study at any stage. Information sheets and ethical approval are provided in Appendix A.

The session consisted of three parts. In the first part, participants first read the information sheet (Appendix A1), and, after all questions had been clarified with the investigator, provided written informed consent (Appendix A2). Afterwards, participants filled in the *visual analogue scales* as a baseline measure of affect, distress, paranoia and loneliness. Then, a series of interviews was carried out to assess both positive and negative symptoms of psychosis (*SAPS*, *SANS*) and social functioning (*TBM*). Afterwards, participants filled in the *CES-D*, the *Multidimensional Support Scale* and the *loneliness* and *confidant* items.

The second part of the session consisted of the experimental picture viewing task. First, participants filled in the *visual analogue measures* again as a second baseline measure, and then watched either of the two picture sets “anxiety” or “neutral / happy”, followed by a 5 minute distraction phase during which participants completed the *verbal fluency task* and filled in the *visual analogue measures* again. Afterwards, participants watched the remaining picture set, and filled in the same *visual analogue measures*.

Finally, participants completed a 10 minute *Visual Attention Task* which was not part of this study and will be reported elsewhere (Dr. Fergus Kane’s DClinPsych project). At the end of the assessment session the investigator debriefed the participant which involved gathering feedback on how they found the session, checking on their well-being and providing a rationale for the study. All participants were provided with information on who they could contact, which included the author of this study and his supervisors, if they were distressed about the assessment. However, none of the participants took up this offer. Finally, participants were reimbursed for their time. The investigator made an entry in the electronic patient notes system for each participant, briefly informing the participants’ care teams about their participation in the study. If participants showed any signs of distress, heightened symptoms, or risk, the clinical care team was informed, in accordance with the study protocol⁹.

Each participant was contacted by telephone one week after the assessment to enquire about their mental health and signpost them to relevant services and support, if required.

⁹ The examiner informed the care team after the session in one case where the participant showed heightened psychosis symptoms.

However, none of the participants had been distressed or negatively affected by the experimental procedure. Figure 2.1 shows the flow chart of the individual steps of the assessment session.

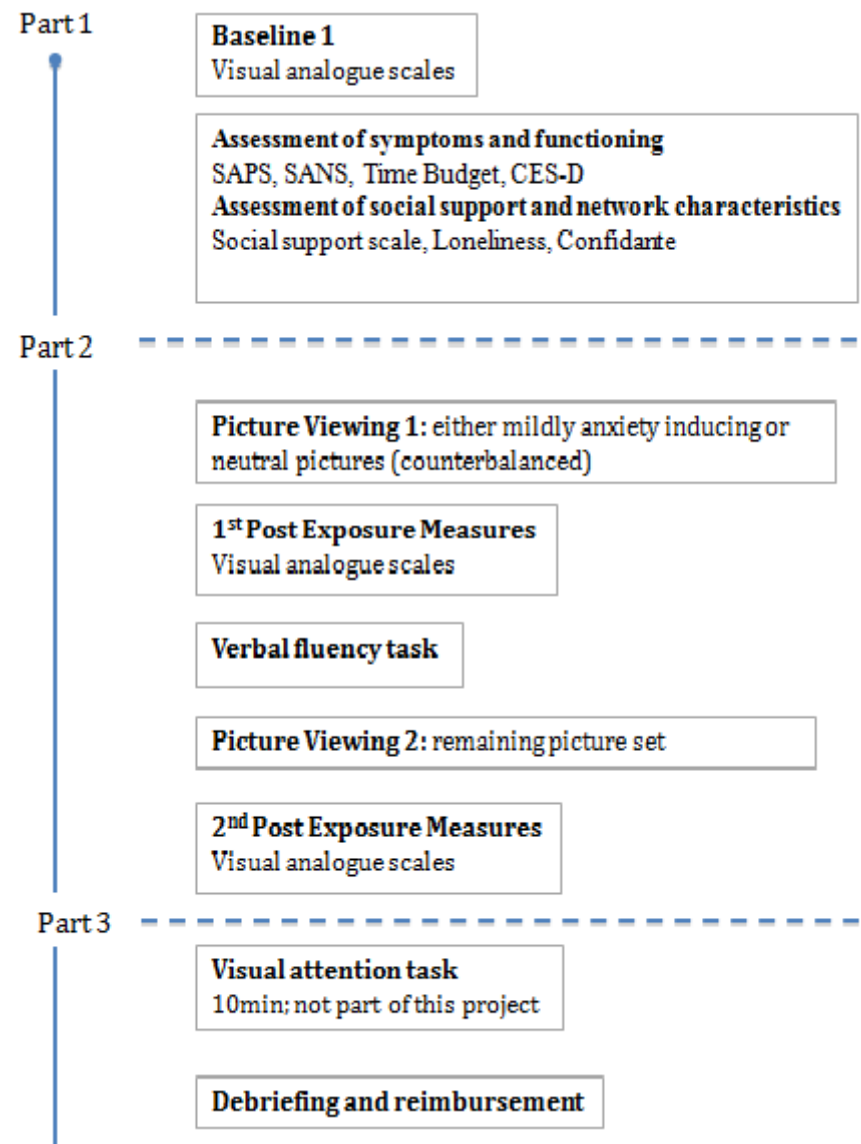


Figure 2-1 Flow chart of assessment session

2.6 Pilot study

A small pilot study ($N = 4$) was carried out to select a suitable sample of pictures that reliably evoke mild levels of anxiety. Participants were contacted through the Psychological Interventions Clinic for Outpatients with Psychosis (PICuP) which provides access to service user consultants¹⁰. The reason for choosing service user consultants over first episode patients was that they may be less vulnerable to the emotional impact of the most arousing pictures, whilst at the same time being able to report what it would be like for first episode psychosis patients to watch these pictures. Participants watched a series of pictures selected from the International Affective Picture System (IAPS) (Lang, Bradley, Cuthbert, & others, 2005) and an online picture database (www.gettyimages.com) on a computer screen and rated each picture in terms of arousal and valence. In addition, participants gave general feedback on each picture advising the examiner on the suitability for use with first episode patients. Pictures were presented for 6 seconds, in randomised order.

Pre-post changes in affect, paranoia and loneliness, were measured with the visual analogue scales both prior to the presentation (baseline) and afterwards. Results are shown in Figure 2.2. The sample was too small to conduct metric analyses, but the descriptive statistics suggest that the anxiety pictures successfully shifted affect, symptoms and loneliness into the hypothesised direction. Service user consultants confirmed that the pictures were suitable to induce mild and transient levels of anxiety. They also gave feedback regarding the procedure of the study (e.g. about the duration of the session, and whether the questionnaires were adequate). They were reimbursed for their time and travel.

¹⁰ Recovered psychosis patients who provide advice to researchers from a service users' point of view

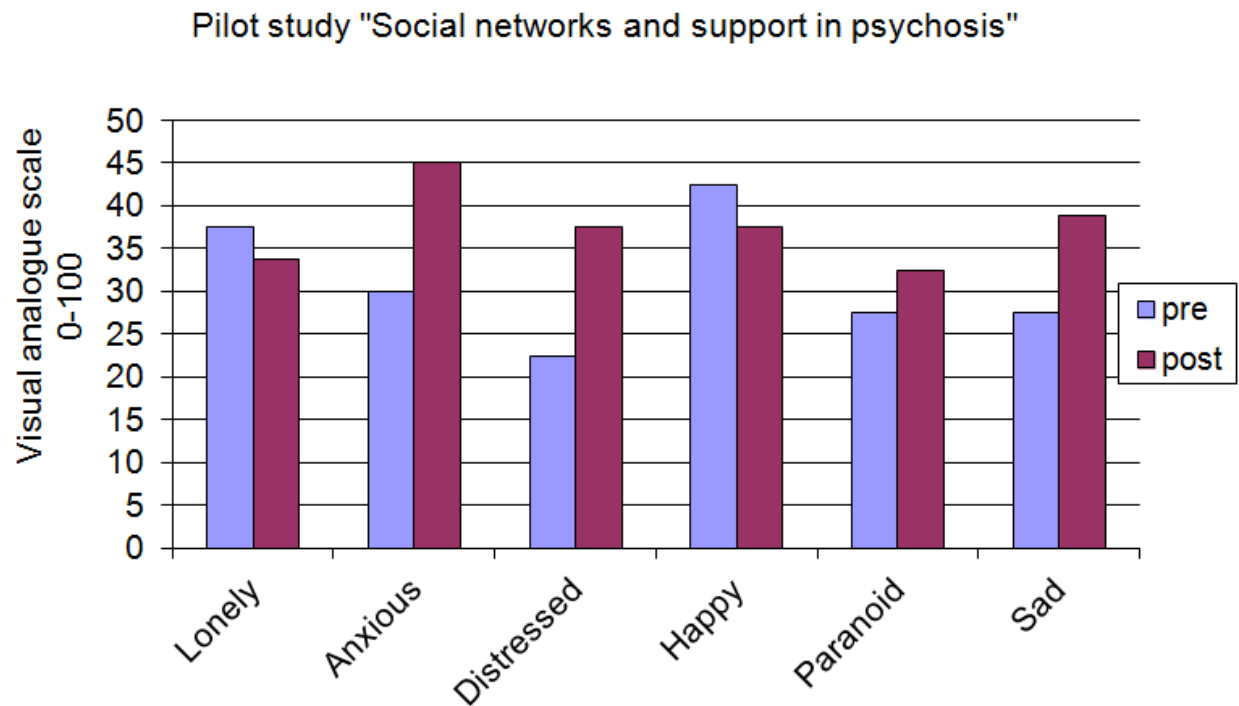


Figure 2-2 Results of pilot study (N=4)

2.7 Power analysis

It was aimed to recruit 40 first episode psychosis patients. Earlier social support and network studies using samples of people with psychosis have found Pearson-correlations (effect sizes) of social network characteristics with symptoms of psychosis between 0.3 and 0.6 (Bengtsson-Tops & Hansson, 2001; Cresswell et al., 1992; Hamilton, Ponzoha, Cutler, & Weigel, 1989). The suggested sample size would be big enough to detect effect sizes of 0.40 with a power of 80% at a conventional alpha level of .05 (Cohen, 1969). Minimum sample size for the experimental part of the study has not been calculated. This is because, to the best knowledge of the author, no study to date has investigated whether induced anxiety mediates between perceived loneliness and paranoia in this particular sample.

2.8 Design and statistical analysis

All analyses were carried out using the Statistical Package for the Social Sciences Version 19.0 (SPSS Institute, Chicago, IL, USA). The Kolmogorov Smirnov test tested whether data was normally distributed. Skewed scores were transformed in order to be normally distributed. Levene's test tested for equality of variances. Significance levels are reported two-tailed; and values of $p < .05$ were considered to be significant.

A cross-sectional correlational design was used to test hypothesised relationships between *perceived social support* and *social network characteristics* with *symptoms* and *functioning* (**Hypothesis 1**). Proposed relationships were tested with Pearson correlations or Spearman's rank correlations if scores could not be transformed into a normal distribution.

A repeated measures ANOVA with the two within factors 'picture type (anxiety versus neutral/ happy) and 'visual analogue scale' tested predicted differences on the visual analogue scales before and after watching anxiety-inducing and neutral / happy pictures. In a second step, this analysis was controlled for potentially confounding variables such as 'order of picture set', DUP, gender, and ethnicity. Hypothesised relationships between transient feelings of *loneliness*, *paranoia* and *anxiety* (**Hypothesis 2**) were tested with a simple mediation model using Preachers and Hayes' (2004) SPSS Sobel-test macro with bootstrapping¹¹. More specifically, it was tested whether the predicted relationship between loneliness and paranoia was significantly reduced when controlling for anxiety. This would indicate that anxiety may be a potential mediator between loneliness and paranoia.

Furthermore, an exploratory step-wise regression analysis tested whether the social support variables predicted perceived loneliness after anxiety-inducing pictures (**Exploratory Hypothesis 3**). This analysis used the change score of loneliness, i.e. the absolute loneliness score after anxiety-inducing pictures was corrected for loneliness at baseline 2 thus reflecting the reactivity to anxious situations.

¹¹ The Sobel test (Sobel, 1982) is widely used in social sciences to assess for mediation effects (Preacher & Hayes, 2004). More specifically, it tests the indirect effect the independent variable has on the dependent variable via the mediator. It has been recommended to use bootstrapping for inference about indirect effects, especially in small to moderate sample sizes (20-80) (Preacher & Hayes, 2004; Preacher & Leonardelli, 2001).

Finally, Pearson correlations or Spearman's rank correlations tested predicted associations between current psychosis symptoms and functioning with induced anxiety and symptoms in the session (**Exploratory Hypothesis 4**).

Effect size: Following the recommendation of Rosenthal (1995), measures of effect size were computed as partial η^2 , which reflects the proportion of total variability attributable to a factor (reported here as effect size η^2 , percentage of explained variance). Referring to Cohen's (1988) convention, effects of $.01 < \eta^2 < .09$ are considered small, $.09 < \eta^2 < .25$ medium and $\eta^2 > .25$ large.

3. Results

Part 1 – Interview and questionnaire data

Clinical characteristics of the sample and social network and social support measures are presented in Table 3.1. The SAPS was completed twice, first retrospectively with regards to the participants' worst part of their first episode, and subsequently for their current presentation. At the time of the assessment, participants presented with significantly fewer positive symptoms as compared to their first episode ($t(36) = 8.7, p < .001$). The sample reported clinically depressive symptoms with the mean CES-D score falling significantly above the cut-off of 16. Overall functioning as measured with the Time Budget Measure was relatively high (see Jolley et al., 2005; mean score of high activity sample = 53), however, activities varied strongly, with some participants spending their time mostly lying in bed compared to others working full time and having an active social life. Thirty four percent of the sample reported that they did not have a confidant.

Table 3-1 Clinical characteristics and social support measures of sample

Variable	Mean (SD), [range]
<i>Psychosis symptoms</i>	
SAPS – worst episode	9.4 (4.2), [0-15]
SAPS - current	2.9 (4.3), [0-15]
SANS – current	5.8 (5.5), [0-19]
<i>Overall functioning</i>	
Time Budget Measure	58.8 (22.9), [11-108]
<i>Depressive Symptoms</i>	
CES-D	21.5 (12.9), [3-52]
<i>Multidimensional Support Scale</i>	
Perceived availability social support - friends & family	15.8 (4.7), [9-24]
Perceived adequacy social support - friends & family	13.9 (3.9), [6-18]
Perceived availability social support - experts	13.9 (4.3), [5-20]
Perceived adequacy social support - experts	12.3 (3.4), [5-15]
Number friends and family seen in the past week	3.9 (4.4), [0-25]
Number of lonely days in the past week	2.6 (2.7), [0-7]
Confidant (Frequency)	No: 13 (34.2%) Yes: 25 (65.8%)

Hypothesis 1: *Positive and negative symptoms of psychosis and overall functioning are related to qualitative aspects of social networks and poor perceived social support. Specifically, low perceived social support, poor perceived adequacy of social support, perceived loneliness and the absence of a confidant will be related to psychosis symptoms.*

Table 3.2 presents the correlations between the clinical variables and social support and network measures. Hypothesis 1 was well supported by the data. Current psychosis symptoms strongly correlated with social support measures, i.e. more positive and negative symptoms were associated with poorer perceived support. More specifically, poor ‘perceived adequacy of social support provided by friends and family’ was associated with more and severe current positive and negative symptoms, but not with positive symptoms of the initial episode. This suggests that participants who were unsatisfied with their perceived support had more psychosis symptoms. Equally, fewer friends seen in the previous week, feeling lonely and not having a confidant were also strongly associated with more severe current positive and negative symptoms and poorer overall functioning. More positive symptoms during their first episode predicted low ‘perceived availability of friends and family’ and lower ‘number of friends and family seen in the previous week’.

Control analyses

Since the associations between social support and network variables may be explained by other factors, control analyses were carried out with a number of potential confounds, namely ‘Duration of untreated psychosis’, ‘Gender’, and ‘Age of onset’ (following Norman et al., 2005). First, it was tested whether any of the potential confounds correlated with either the support or symptom variables. In case of significant correlations, partial correlations tested whether significant associations between support and symptom variables (see Table 3.2) were affected by potential confounds.

‘Duration of untreated psychosis’ (DUP) was significantly associated with more current positive symptoms (SAPS, $r = .59, p < .001$), and depression (CES-D, $r = .43, p = .01$) but not with current negative symptoms (SANS, $r = .26, p = .13$). DUP was also negatively associated with ‘Perceived availability of support by friends and family’ ($r = -.48, p = .003$) and ‘Perceived adequacy of support by friends and family’ ($r = -.39, p = .02$), but only revealed a trend for a correlation between ‘Number of lonely days’ ($r = .27, p = .1$) and

‘Confidant’ ($r = -.31, p = .07$). Neither, ‘Gender’ and ‘Age of onset’ were associated with the support nor the symptom variables ($.07 < p < .95$). Partial correlations found that the associations between ‘Perceived adequacy of support by friends and family’ with SAPS and CES-D (see Table 3.2) were not affected by DUP.

Additional exploratory analysis

An exploratory t-test compared participants with and without a confidant on number of lonely days in the previous week. Those participants without a confidant reported significantly more lonely days than those with a confidant ($t(36) = 3.25, p = 0.002, \eta^2 = .23$).

Table 3-2 Associations of current psychosis symptoms, overall functioning and depressive symptoms with social support and network variables. Significant correlations are presented in bold.

Symptoms and functioning	Perceived availability of social support (family & friends)	Perceived adequacy of social support (family & friends)	Perceived availability of social support (experts)	Perceived adequacy of social support (experts)	Number of friends & family seen in past week*	Number of lonely days in past week	Confidant**
SAPS	-.22	-.35*	-.30	-.28	-.33*	.41*	-.40*
SANS	.09	-.38*	.08	.06	-.19	.46**	-.43**
Time Budget	-.00	.29	-.03	.00	.33*	-.30	.29
CES-D	-.24	-.60**	-.30	-.45**	-.28	.66**	-.49**

* Spearman's rank correlations are reported

**Point-biserial correlation; binary variable coded with 0=no confidant, 1=confidant, hence negative correlations with symptom scores indicate participants with no confidant have more symptoms. Positive correlations with the Time Budget Measure indicate that those without a confidant have poorer functioning.

Note, significant correlations are indicated with * p<.05, ** p<.01

Part 2 - Mood induction task

Figure 3.1 shows the absolute ratings on the visual analogue scales after anxiety-inducing and neutral/happy pictures. Differences on the scales were tested with a repeated measure ANOVA with the two within factors 'picture type (anxiety versus neutral) and 'Visual analogue scale'. There was a main effect for 'picture type' ($F(1, 37) = 17.6, p < .001, \eta^2 = .32$) and a significant interaction between 'picture type' and 'Visual analogue scale' ($F(5, 33) = 4.9, p = .002, \eta^2 = .42$). Planned follow-up contrasts showed that after watching anxiety pictures, participants reported significantly more state anxiety, distress, sadness and paranoia and significantly less happiness than after watching neutral pictures (all p 's $< .001$) suggesting that the experimental mood induction worked well. Levels of perceived loneliness after watching anxiety pictures were not significantly different than after watching neutral pictures ($p = .31$).

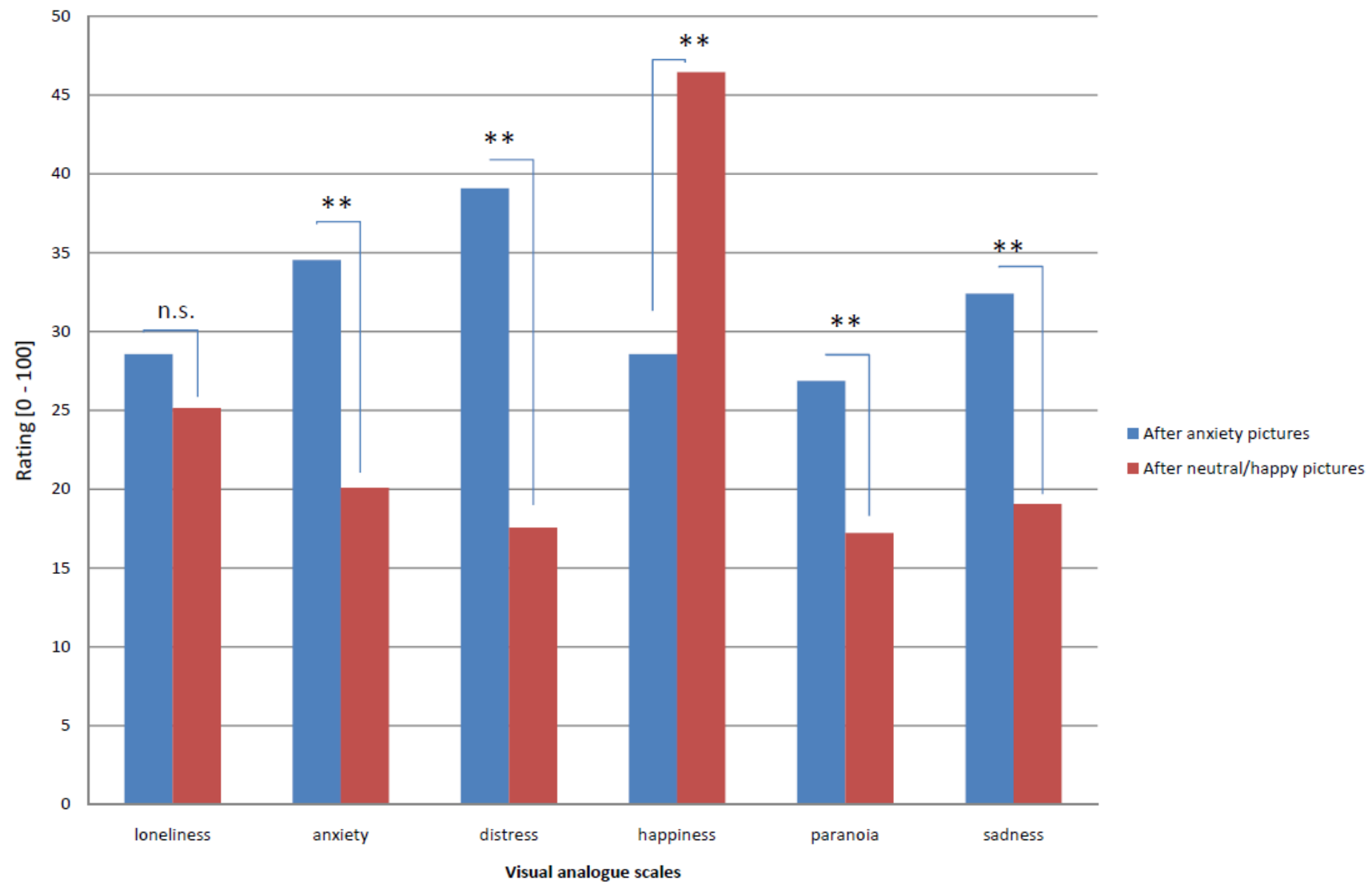


Figure 3-1 Absolute ratings on the visual analogue scales after watching anxiety-inducing pictures and after neutral /happy pictures

Control analyses

To test whether 'order of picture set' influenced the mood induction, a repeated measures ANOVA with 'picture type (anxiety versus neutral)' and 'Visual analogue scale' as the within factors, and 'order of picture set' (anxiety pictures presented first versus neutral pictures presented first) as the between factor was computed. There was no main effect for 'order of picture set' ($F(1, 36) = .64, p = .43, \eta^2 = .02$). Equally, 'order of picture set' did not interact with 'Visual analogue scale' ($F(1, 36) = .23, p = .95, \eta^2 = .03$), and only revealed a trend for an interaction with 'picture type' ($F(5, 32) = 3.36, p = .08, \eta^2 = .09$). Bonferroni-controlled post-hoc analyses revealed that participants who saw the 'neutral pictures' first reported significantly more anxiety after 'anxiety pictures' than those who saw the 'anxiety pictures' first ($p = .01$). Therefore, 'order of picture set' was controlled for in the following analyses where appropriate. It was further checked whether any of the following potentially confounding variables interacted with the variable picture type: 'gender', 'DUP', and 'Ethnic group'. Since no significant effects emerged, these variables were not controlled for in the following analyses.

Hypothesis 2: *Predicted associations between feeling lonely and feeling paranoid after anxiety-induction are significantly reduced when controlling for anxiety (mediation analysis).*

First, Pearson correlations showed, as expected, that feelings of loneliness were significantly associated with feelings of paranoia after anxiety-induction ($r = .71, p < .001$). Second, the Sobel test was carried out with loneliness as the independent variable, paranoia as the dependent variable and anxiety as the putative mediator variable. In line with the hypothesis, Sobel test was highly significant thus confirming the indirect mediation effect ($ab = .43, z = 3.5; p < .001$) suggesting that the pathway between feeling lonely and feeling paranoid was mediated by anxiety. The mediation model is shown in Figure 3.2.

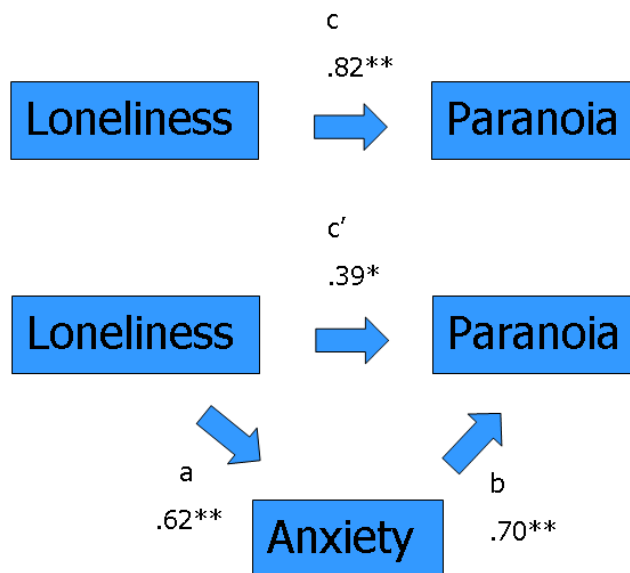


Figure 3.2. Results of the hypothesised mediation model with anxiety as a mediator between loneliness and paranoia (numbers represent the partial regression coefficients). The correlation between loneliness and paranoia dropped significantly when controlling for anxiety thus suggesting that anxiety may function as a partial mediator. ** $p < .01$

Since some participants also reported feeling lonely and paranoid after the neutral/ happy pictures, the parallel Sobel test tested whether a potential relationship between loneliness and paranoia was mediated by anxiety. Again, there was a significant association between loneliness and paranoia ($r = .39$, $p = .02$), and in line with the hypothesis, the Sobel test revealed anxiety as a putative mediator ($z = 2.8$, $p = .004$), thus further corroborating the hypothesis that anxiety explains, at least in part, the relationship between loneliness and paranoia. Controlling for order of picture set did not affect the results.

Exploratory Hypothesis 3: *Those participants with poor perceived social support are more easily induced by negative affect into perceived loneliness than those with high perceived support.*

An exploratory linear regression analysis tested the relative contribution of the social network and support variables to the prediction of perceived loneliness after exposure to anxiety-inducing pictures. The following support variables were entered into a step-wise regression model: 'Perceived availability of social support from family & friends', 'Perceived adequacy of social support from family & friends', 'Perceived availability of social support from experts', 'Perceived adequacy of social support from experts', 'Number of friends and family seen in the past week', 'Number of lonely days in the past week', and 'Confidant'. The absence of a 'Confidant' explained 13% of the variance ($R = .34$, $F(1, 34) = 4.2$, $\beta = .34$; $p < .049$), and was therefore kept in the model. All other variables were dropped from the model since they did not predict unique variance over and above what could be explained by 'Confidant'. This suggests that participants who did not have a confidant were more likely to feel lonely when feeling anxious than those with a confidant. Assumptions of the regression model were not violated.

Exploratory Hypothesis 4: *Those participants who are more easily triggered into anxiety have temporarily raised rates of subsequent paranoia. Furthermore, participants with high current psychosis symptoms are more easily triggered into feeling anxious and paranoid.*

In line with the Exploratory Hypothesis 4, Pearson correlations showed that induced anxiety was strongly associated with elevated transient feelings of paranoia ($r = .46$, $p < .001$; $r = .57$, $p < .001$). In addition, participants with heightened current negative symptoms were more easily triggered into feeling paranoid ($r = .36$, $p = .025$), but not into feeling anxious ($r = -.15$, $p = .37$; $r = -.12$, $p = .48$), thus providing partial support for the hypothesis. Since people with psychosis commonly suffer from depression, and because emotional changes have been suggested as one mechanism in the formation and maintenance of psychosis (Garety et al., 2001), the author also looked at the associations of depression with elevated paranoia after anxiety induction. As expected, participants with higher levels of depression, felt more paranoid after watching anxiety-inducing pictures ($p = .46$, $p = .005$).

However, current positive symptoms did not increase the likelihood of feeling paranoid after anxiety induction ($r = .20, p = .24$). Correlations are provided in Table 3.3.

Table 3-3 Associations of induced anxiety, paranoia and distress with psychosis symptoms, overall functioning and current depression

	(1) Anxiety*	(2) Paranoia*	(3) SAPS	(4) SANS	(5) Time Budget
(1) Anxiety*					
(2) Paranoia*	.33*				
(3) SAPS	-.15	.20			
(4) SANS	-.15	.36*	.30		
(5) Time Budget	-.11	-.33*	-.27	-.71**	
(6) CES-D	-.00	.46**	.49**	.55**	-.39*

* Measured after anxiety-inducing pictures and corrected for baseline (change scores)

Note, significant correlations are indicated with * $p < .05$, ** $p < .01$

4. Discussion

The present study combined interview and questionnaire measures with a mood induction task to investigate social network and social support characteristics in participants with first episode psychosis. In particular, the study aimed to (1) replicate associations of social network and support variables with psychosis symptoms in a first episode group and (2) to study one potential mechanism (i.e. anxiety) that may mediate the link between one social network characteristic (loneliness) with one psychosis symptom (paranoia).

Associations of social network and social support with psychosis symptoms

Consistent with Hypothesis 1, poor perceived social support, loneliness and the absence of a confidant significantly predicted current psychosis symptoms. These findings are in part a replication of the well established finding that poor social network and support relate to poor mental health in general (Greenblatt et al., 1982; Holt-Lunstad et al., 2008) and heightened psychosis symptoms in particular (e.g. Norman et al., 2005; Angell and Test, 2002; Salokangas et al., 1997). These findings also extend the current literature on social support in psychosis. While the majority of social support and psychosis studies drew on data from long term (chronic) patients, this study builds on the emerging evidence that has identified associations between symptoms and social support in people with first episode psychosis. Furthermore, this study used a mixture of social network and support measures capturing both functional aspects of supportive relationships (perceived availability of social support, perceived adequacy of social support), and qualitative aspects (confidant, loneliness) thus providing a broader picture than previous studies about how the perception of social support relates to current psychotic symptomatology. In addition, poor current social support was associated with longer duration of untreated psychosis, which complements previous studies showing that the low perceived social support from family and friends is linked with longer DUP (Morgan et al., 2006), and suggests that longer DUP may have damaging social effects after a first episode.

In terms of perceived social support, satisfaction (perceived adequacy) with perceived social support, rather than perceived availability of it, was associated with more current positive and negative psychosis symptoms. More precisely, those participants who were unsatisfied with their social support from friends and family had more psychosis symptoms and were significantly more likely to be depressed than those who were satisfied with their social support. This finding is in line with Norman et al.'s (2005) study of first episode patients that also found lower satisfaction with social support to be predictive of more

positive symptoms. The results are also consistent with Winefield and colleagues' (1992) original data which showed that higher satisfaction with supportive relationships was inversely related to levels of depression.

The finding that both current positive and negative symptoms were associated with low satisfaction of perceived social support is in line with more recent studies that also found an association between poor perceived social support and more negative and positive symptoms (e.g. Angell and Test, 2002). As pointed out by Angell and Test (2002), methodological differences may explain the fact that older studies predominantly found associations between poor social support and negative symptoms, but not with positive symptoms (e.g. MacDonald et al., 1998). For example, the majority of older studies assessed chronic patients with a longstanding illness history as opposed to first-episode patients (e.g. Hamilton et al., 1989), which may explain differences in presentation of positive and negative symptoms. Also, previous studies tended to focus on assessing *received* social support as opposed to *perceived* social support and its satisfaction with it, which has been argued to be a more adequate measure of social support (Winefield et al., 1992; Ibarra-Rovillard & Kuiper, 2011). Finally, different symptom measures (categorical vs. continuous) may also account for differences in the observed correlations. It is plausible to assume that continuous measures (e.g. SAPS or SANS) not only fit better with current dimensional understandings of psychosis (Kuipers et al., 2006; Van Os et al., 2010), but are also more sensitive to capturing the variety of symptoms.

The author did not find any significant associations between perceived social support from professionals and psychosis symptoms. This may be due to a number of reasons. First, not all participants were currently under the care of a mental health team and some participants tended to have irregular contact with mental health experts. Therefore, the observed null-effect may simply reflect a floor effect. Secondly, it is conceivable that perceived support provided by one's social network (friends and family) matters more to our mental well-being than the perceived support provided by experts (see Helgeson, 2003). It is possible that while practical and informational support obtained from mental health practitioners is important, it is the perceived support from our friends and family that matters most for a service user's day-to-day coping, particularly when contact with services is limited. This would also be consistent with Thoits (2011) assertion that the two groups that are most effective in providing social support and providing active coping assistance and emotional sustenance are *significant others / close friends* and *others with similar experiences*.

In line with Hypothesis 1, both psychosis symptom clusters were associated with loneliness. Those participants who reported more loneliness in the previous week were more likely to also report more current psychosis symptoms. This finding further extends the current literature and links in with Neelman and Power's (1994) interview-based study who found that people with psychosis felt particularly lonely as compared to other patient groups. While their study compared loneliness across patient groups, this study further demonstrated that loneliness predicted psychosis symptoms. This finding also highlights the overall importance that loneliness has for our mental well-being (Thoits, 2011), and is consistent with evidence from studies investigating loneliness in other patient and non-patient samples (e.g. Heinrich and Gullone, 2006; Ernst and Cacioppo, 2000).

Furthermore, this study also found that a very high number of people in this sample did not have someone to confide in. In this sample more than 1/3 of the participants reported a lack of a confiding relationship, and it was these people who had elevated current psychosis and depressive symptoms. Not having a confidant and feeling lonely are highly related (Green et al., 2001), and an exploratory analysis showed that those without a confidant reported significantly more lonely days than those with a confidant. This extends the current psychosis literature, since previous studies on confidants have almost exclusively been undertaken with depressed patients (e.g. Diwan et al., 2007). The finding also complements Salokangas et al.'s (1997) study, which showed that over a 5 year follow-up period, people with psychosis who were living with a spouse had better clinical and functional outcome than those without a spouse. Although the project did not obtain quantitative data on the distress associated with not having a confidant, some participants reported that they found the absence of a confidant upsetting. Ibarra-Rovillard and Kuiper's (2011) recently suggested that it is the fulfilment of psychological needs through which social relationships exert their effect on our well-being. Being without someone to trust and to confide in, or feeling lonely and isolated, may be illustrative of how this very basic need may be thwarted continuously in this particular population. In fact, the absence of confiding relationships is regarded as an established risk factor for depression (Bebbington, Tennant, Sturt, & Hurry, 1984; Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006) and possibly increases the risk for psychosis (Salokangas et al., 1997).

Inspecting associations of clinical symptom measures with the support variables, it is noticeable that depression was the single strongest predictor of poor social support,

loneliness and absence of a confidant. The finding that depression revealed stronger correlations with social support variables than psychosis symptoms may be explained by the fact that a large proportion of the sample was currently in remission and recovering from their first episode, but still suffered from clinically low mood (as indicated by the CES-D, the score average for the current sample fell above the clinical cut-off). Hence, more variation in the CES-D may also statistically explain why depression was more strongly correlated with social support than psychosis symptoms. Although depression and loneliness are seen as different constructs in the literature, it has been argued that both constructs share similar features (Heinrich and Gullone, 2006). The high correlation between depressive mood and perceived inadequacy of social support provided by friends and family ($r=.60$), highlights the importance of satisfying supportive relationships. Note, depression did not appear to be associated with perceived availability of social support from friends and family. Yet again, this strongly supports the notion that it is indeed satisfaction with perceived social support, rather than its perceived availability that impacts most on subsequent low mood (see also Winefield et al., 1992). It is likely that many people with psychosis do in fact have social support in place (Forrester-Jones et al., 2011), but this may not be beneficial for their mental-health if the social support is seen as poor and inadequate, and as a consequence may increase the risk of depression. Depressive mood, in turn, is one affective factor that has been found to drive psychotic symptoms (Birchwood & Iqbal, 1998b; Freeman & Garety, 2003; Krabbendam et al., 2005).

This study also incorporated an indicator of overall social and occupational functioning (Time Budget, Jolley et al., 2005, 2006). It was hypothesised that poor overall functioning would be related to poor social support, loneliness and not having a confidant. Although low overall functioning was significantly associated with fewer friends seen in the previous week, it was statistically not associated with the other social support variables and loneliness. This is in contrast to previous literature (e.g. Faccincani et al., 1990; Salakongas et al., 1997). However, it is important to note that the pattern of the direction of the non-significant correlations pointed in the hypothesised direction, with most correlations reaching near significance, hence those analyses may have simply been under-powered. The finding that number of friends seen in the past week revealed the strongest correlation with functioning is not surprising, given that spending time with friends was an activity that revealed high scores on the Time Budget measure. Future studies should further assess the role of overall functioning for perceived social support to build on this emerging evidence.

In an attempt to shed some light on the question of how loneliness may link with psychosis symptoms, a mood induction task was used to study one potential mediator (anxiety) between loneliness and paranoia.

Anxiety as a potential pathway between loneliness and paranoia

As expected, loneliness was highly associated with paranoia and, in line with Hypothesis 2, this effect was mediated by feelings of anxiety. This finding suggests that anxiety may indeed be one potential pathway through which loneliness may drive paranoia. There is a general shortage of studies investigating pathways for the well established finding that poor qualitative network features such as loneliness relate to poor mental health (Heinrich & Gullone, 2006). More specifically, to the knowledge of the author, no study to date has examined particular pathways between feeling lonely and feeling paranoid. Therefore, this study extends the current literature and marks an initial attempt at closing this knowledge gap.

The proposal that anxiety may be a possible mediator between loneliness and paranoia was based on clinical observations, experimental studies, and recent theoretical conceptualisations of psychosis.

How does loneliness increase anxiety?

It was suggested that loneliness may distort thinking processes by exaggerating threat appraisals (Hawkley et al., 2003). Alternatively, lonely people may find it harder to think of alternatives to their unusual ideas which may raise anxiety levels and in turn exacerbate psychosis symptoms (Garety et al., 2001, Freeman et al., 2007).

Although findings from the mediation analysis are encouraging, it is important to emphasise that they need to be interpreted cautiously and can only be seen as preliminary, for a number of reasons. First, the mediation design is ultimately correlational in nature, and it is therefore possible that an unknown third variable accounts for the observed relationship patterns. For example, it is conceivable that loneliness is more strongly related to affective states other than anxiety, such as depression (Birchwood et al., 2007), which in turn drives psychotic symptoms. Also, loneliness may itself be a mediating pathway between poor social support and paranoia. Poor social support may directly disrupt a sense of belongingness and thereby increase feelings of loneliness (Thoits, 2011). Furthermore, this design did not account for temporal precedence of the variables under investigation, i.e. the measurement of loneliness, anxiety and paranoia occurred simultaneously thus

making it impossible to draw causal conclusions from the results. From an experimental point of view it would have been desirable to manipulate feelings of loneliness to test whether such an increase led to heightened anxiety. However, for ethical reasons the study abstained from such a manipulation. Note, other researchers have concluded that loneliness cannot be readily manipulated under controlled conditions and therefore the research focus should be on detecting variations in loneliness (Russell et al., 1980). On the other hand, anxiety induction using pictures is well-established and known to evoke transient effects. For this reason, the study chose the experimentally less powerful design at the cost of drawing weaker causal conclusions. Despite the limitations of the experimental design, it is still plausible to tentatively interpret anxiety as a possible mediator. There is good evidence in the literature that anxiety drives psychotic symptoms, especially paranoia (Freeman et al., 2007), and it is plausible that anxiety may be, at least in part, driven by loneliness (Hawkley et al., 2003). More research into the pathways of loneliness and paranoia, ideally using true experimental designs, is clearly indicated to deepen our understanding of how both concepts might be interrelated. In addition, qualitative research into loneliness, anxiety and psychosis may help to refine future hypotheses.

The exploratory regression model found that absence of a confidant predicted higher levels of perceived loneliness after anxiety induction. Those participants without someone to confide in were more likely to feel lonely when feeling anxious. Note, this analysis does not report the absolute loneliness score, but the change score (i.e. absolute score corrected for baseline), and therefore reflects reactivity to anxious situations. Since this is an exploratory analysis great caution is required when interpreting this result. Because the effect is very small, it is a real possibility that the effect may have been found by chance. Despite this, the finding provides some evidence that might help us begin to understand how the absence of a confidant may exert its influence on mental health. Anxiety may also, in part, drive loneliness, and it appears that those individuals without someone to confide in are at risk of feeling lonely and anxious. It is also conceivable that anxiety and loneliness may interact in a mutually reinforcing fashion.

Furthermore, the study provides some tentative experimental evidence for recent cognitive models of positive symptoms (Garety et al., 2001; 2007) emphasising the importance of anxiety in symptom formation and maintenance. In line with the Exploratory Hypothesis 4, those participants who were more easily triggered into anxiety reported temporarily raised feelings of paranoia. This suggests that high anxious reactivity may be a vulnerability

factor for experiencing paranoid thoughts. This finding is in line with work from Freeman and colleagues who showed that paranoia is driven by anxiety (e.g. Freeman, 2007).

Furthermore, those participants who had elevated current negative psychosis symptoms felt more paranoid after anxiety-induction than those with lower negative symptoms. However, current positive symptoms were unrelated to heightened paranoia after anxiety-induction. This may be due to floor effects as most participants were in remission and reported only few current positive symptoms, and relatively more current negative symptoms. On the other hand, those with negative symptoms may be more likely to feel lonely and may therefore be more at risk of developing paranoia when feeling anxious. Again, caution is required when interpreting these preliminary findings until they have been replicated in future studies.

Strength and Limitations

The current study has strengths and limitations. Among its strengths is the combination of interview and questionnaire measures with an experimental mood induction task. In addition, this study used a mixture of social support measures and network variables thus providing a richer picture of the participants' supportive relationships than previous studies. Also, to the best knowledge of the author, the study is the first to examine one potential pathway (anxiety) between loneliness and paranoia.

A number of limitations are noteworthy.

Firstly, the study design is cross-sectional. Therefore, no causal direction can be inferred and caution is warranted when interpreting the data. It is unclear from the interview data whether poor social support predated psychosis symptoms, whether symptoms resulted in poor social support, or whether an interaction between both sets of variables operated in a mutually reinforcing fashion, i.e. led to a deterioration of both symptoms and social support.

Secondly, this study presents a large number of correlations between social support and symptom measures thereby significantly increasing the risk of multiple testing. Given the risk of alpha inflation, caution is warranted when interpreting findings from the current study.

Thirdly, the study did not systematically assess individual appraisals of the pictures in the mood induction task. This would have been desirable since some participants reported that (a) the neutral / happy pictures made them feel lonelier and more paranoid than the anxiety-pictures because those pictures reminded them of what they lack in their lives or

(b) triggered paranoid rumination about why we showed them those pictures. This highlights the fact that a broad range of cues can trigger symptoms in psychosis and emphasises the importance of individual appraisals in triggering and maintaining symptoms. Future studies using picture mood induction tasks should assess appraisals of the stimulus material.

Fourthly, for reasons of parsimony this study did not assess perceived social support from peers, but only for family and close friends, and professionals. Since social support from family and close friends is likely to be perceived differently from those provided by peers, it is possible that this study did not comprehensively capture the social support perceived by this sample. It is conceivable that some participants reported being unsupported by their family and close friends, but in fact felt supported by their peers. Future studies should ideally include an additional measure of social support from peers.

Fifthly, it is questionable how representative the current sample was of the first-episode psychosis population as the mean age of 32 (range 21-56) appears rather high as compared to other first-episode studies, e.g. Norman et al. (2005) report a mean age of 25.8 (range 15-47) and Norman, Townsend & Malla (2001) report a mean age of 26.7 (range 16-54). This seemingly higher age is likely to be explained by the recruitment procedure and the inclusion criteria. All participants were referred from Dr Morgan's study which only included participants aged 18 or older thus somewhat skewing the sample as onset of first-episode often occurs within late adolescence (e.g. Häfner, Maurer, Löffler, & Riecher-Rössler, 1993). Also, functioning appeared high in this sample, but is in line with other psychosis studies (Jolley et al., 2005) and reflects the fact that a great proportion of this sample was in remission.

Finally, it would have been desirable to include a healthy control group. This would have allowed an investigation of whether mood induction would trigger feelings of paranoia and loneliness in the general population, which would allow generalising findings more broadly and also provide further support for the dimensional model of psychosis.

Clinical implications

Results of the current project have some implications for clinical practice and research. The two main findings are that (1) poor perceived social support, loneliness and the absence of a confidant strongly relate to psychosis symptoms in first-episode patients, and (2) that anxiety may be one potential mediator between loneliness and paranoia.

Since perception of support, loneliness and the presence of a confidant were assessed with a relatively simple and brief measure, they may be suitable for routine clinical practice, to complement assessment of clients with psychosis and provide an effective outcome measure for treatment and research. Results from this study particularly suggest focusing on measuring the actual experience of social support, i.e. how satisfied clients are and how lonely they feel in their day-to-day lives rather than the perceived availability of social support. Also, asking clients directly whether they have anyone to confide in may provide useful clinical information when formulating and treating the client's difficulties. Furthermore, a better understanding of the mechanisms by which poor perceived social support and loneliness make psychosis symptoms worse may help to design more effective interventions. Results of the current study may inform treatment strategies directly attempting to change the clients' network such as befriending or help to re-appraise existing relationships. With regards to using befriending the current study suggests that the focus should be on finding a person that can help to build a confiding relationship with the client. Befrienders should ideally have had similar experiences mental health like the client because according to Thoits (2011) similar others are in the best position to provide effective emotional sustenance and active coping assistance. There is some evidence for the effectiveness of befriending (e.g. Jackson et al., 2008), and it would be hoped that taking the above suggestions may help to further improve these treatment strategies. Other strategies to directly address poor social network functioning in therapy (e.g. by improving social skills, or facilitating social support) has proven to be difficult (Kawachi & Berkman, 2001; Meltzer et al., 2012). Therefore, it would be desirable to think of alternative approaches. The finding that loneliness may trigger anxiety which in turn drives paranoia is in line with contemporary cognitive models of psychosis (e.g. Garety et al., 2001; Birchwood et al., 2003) emphasising the role of cognitive and affective appraisals of the unusual experience in the formation and maintenance of symptoms. The results from this study suggest that it may be more fruitful to directly target dysfunctional appraisals of relationships and of loneliness. This is also in line with research showing that loneliness is more influenced by subjective appraisals of the social relationships than by its objective

features (Heinrich and Gullone, 2006); and is also in agreement with a recent meta-analysis of intervention studies targeting loneliness (Masi, Chen, Hawkley, & Cacioppo, 2011) which concluded that addressing dysfunctional social cognitions was more effective in reducing loneliness than focusing on enhancing social support, social skills or increasing social interactions. Equally, Meltzer and colleagues (Meltzer et al., 2012) recently concluded in their large epidemiological national survey that interventions focusing on improving social skills or improving the individuals' network are less likely to be beneficial in reducing loneliness than cognitive techniques such as identifying negative automatic thoughts or cognitive restructuring. For example, clients who experience paranoid thoughts about their social relationships may benefit from carefully and gently examining the evidence for and against their beliefs for example by using behavioural experiments or Socratic dialogues. These cognitive techniques could help the client to re-appraise their social relationships in a more benign and less threatening way. Hence, loneliness and its appraisals may be candidate outcome variables for cognitive interventions focusing on improving satisfaction with the participants' relationships and their support. However, further research may clarify how people with psychosis appraise their experience of loneliness and how this may make them feel anxious and in turn paranoid. Future social support and network studies may also focus on symptoms other than psychosis such as distressing voices and their function in addressing loneliness.

Conclusions

This project examined aspects of social support and loneliness in first episode psychosis by combining interview and questionnaire measures with an experimental mood induction task. In line with previous studies, poor perceived social support, loneliness and not having a confidant were associated with psychosis and depression. The second part of the thesis addressed the question of how loneliness might relate to paranoia. Preliminary data suggests that anxiety may be one potential mediator. Exploratory analyses found that those participants without a confidant were more likely to feel lonely when being anxious. Finally, the study provided tentative experimental evidence for recent cognitive models of positive symptoms (Garety et al., 2001), by showing that (a) those participants who are more easily triggered into anxiety have temporarily raised paranoia, and (b) those who have higher current psychosis symptoms are more easily triggered into paranoia.

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6 Appendix

Appendix A

Appendix A1 *Information sheet*

Appendix A2 *Consent form*

Appendix B

Appendix B1 *Scale for the Assessment of Positive Symptoms*

Appendix B2 *Scale for the Assessment of Negative Symptoms*

Appendix B3 *Time budget measure*

Appendix B4 *Visual analogue scales*

Appendix B5 *Center for Epidemiologic Studies Depression Scale*

Appendix B6 *Social Support Scale, Loneliness and Confidante item*

Appendix C

Appendix C1 *Description of pictures used in experimental task*

SOCIAL NETWORKS AND SUPPORT IN PSYCHOSIS - STUDY A

Participant Information Sheet

Version 2 – 14/04/11

Study No – 11/LO/0573

Please take time to read the following information carefully.

You are invited to take part in a research study. This study is Oliver Suendermann and Dr Fergus Kane's Doctorate in Clinical Psychology research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish – you can seek independent advice about participating in the study from the South London and Maudsley NHS Patient Advisory Liaison Service (PALS) or the Research and Development office. Please ask the researcher if you would like their contact details.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more information about the study, about confidentiality, and how to complain if there are problems.

Ask us if there is anything that is not clear or if you would like more information. Please take your time to decide whether or not you wish to take part. Thank you for taking the time to read this.

Part 1

What is the purpose of the study?

This study is about the importance of relationships. There are 2 parts to it, study A and study B. In study A we are particularly interested in how symptoms of psychosis and mood affect relationships. We hope that this will help us to improve talking treatments for people with psychosis.

We may also invite you to participate in study B. This will involve attending three meetings to talk about your relationships and how to improve them.

What will the study involve?

Study A: you will meet with the researcher once.

(1) At the beginning, you will be asked to talk a bit about some of your thoughts, feelings and experiences. We will also ask you about your relationships and your activities in your day. You will then answer some questionnaires; one is about your mood, one is about your background (e.g. when you were born) and one is about some of your beliefs you hold about yourself and others.

Appendix A1

(2) Secondly, you will be asked to watch some pictures on a computer screen. Some of these may make you feel slightly anxious, others will not. After watching the pictures you will be asked about your mood, your thoughts and your experiences.

(3) Then you will be asked to remember some words and to write them down (or say them if you prefer).

Once we have done all this, you will complete a calm and relaxing activity.

In total, the entire session will take up to 1.5 hours. You will be able to take breaks any time you wish and stop the session at any point without giving a reason.

Why have I been chosen?

We are recruiting people from mental health services in South London, who hear voices or have upsetting thoughts.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you do take part, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your care in any way.

Will I be paid?

We will pay you £20 for your time, travel, and refreshments.

What happens to the information I provide?

All your answers are strictly confidential. However, the researcher will tell your clinical team about any important disclosure that is relevant to your care.

What are the possible disadvantages and risks of taking part?

We do not think that participating in this study will be harmful in any way. However, if you find anything upsetting, at any stage, please let the researcher know (details below) or talk to your doctor or care-coordinator. To check how you are, the researcher will call you, if you agree, one week after the study.

What are the possible benefits of taking part?

We do not expect study A to directly help with your care, although it will help us to develop new talking treatments. Many people report that they find answering questions and completing these kinds of activities useful and interesting.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

We will inform your clinical team that you are taking part in the study. Otherwise, all the information about your participation in this study will be kept strictly confidential. The details and exceptions to this are included in Part 2.

This completes Part 1 of the Information Sheet.

Appendix A1

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

Complaints: If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions (Contact details are below and in Part 1). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from your local hospital or team base.

Harm: In the unlikely event that you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against your local NHS Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential, i.e. all your answers to the questionnaires and the tasks will be kept anonymously and will be identifiable only by a number, not by your name. Paper copies of questionnaires will be kept securely by the researchers in a locked filing cabinet in a locked office.

The information you give will be available only to the research team. However, the researcher will let your team know that you are taking part in the study. Should you give any information, such as criminal disclosures, or information relating to your own or others safety, which requires action, including passing on information to others, the research team will take this action as appropriate.

What will happen to the results of the research study?

We intend to publish the results of the research. You will not be personally identified in any report/publication. If you would like to receive a copy of the results of the research please let the researcher know so that she can arrange this for you. Once the study has finished we also plan to publish a summary of our findings on the website www.mentalhealthcare.org.uk

Who has reviewed the study?

The study was reviewed by researchers at the Institute of Psychiatry. It has also been reviewed and given a favourable opinion by the South East London Research Ethics Committee (REC 4).

How can I take part?

If you would like to take part in this project, please complete the attached consent form. You will be given a copy of the information sheet and a signed copy of the consent form to keep. If you have any questions or concerns about taking part please contact the researcher below.

Contact Details: Dr. Oliver Suendermann, Trainee Clinical Psychologist, e-mail: oliver.suendermann@kcl.ac.uk address: PO78 Institute of Psychiatry, De Crespigny Park, Denmark Hill, London. SE5 8AF.

Dr. Fergus Kane, Trainee Clinical Psychologist, on 0777 1933738 (e-mail: fergus.kane@kcl.ac.uk) address: PO78 Institute of Psychiatry, De Crespigny Park, Denmark Hill, London. SE5 8AF.

Participant Information Sheet

Version 2 – 14/04/11

Study No – 11/LO/0573

CONSENT FORM

SOCIAL NETWORKS AND SUPPORT IN PSYCHOSIS – STUDY A

Name of researcher: Oliver Suendermann

Please initial boxes:

1. I confirm that I have read the information sheet dated 14/04/11 for the above study. I have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I am willing for the researcher to contact my team to let them know I am taking part in the study. ☐
4. I am willing for the researcher to contact my team with any information relevant to my care, should this become apparent while I am taking part in the study. ☐
5. I understand that sections of my medical notes and data collected during the study, may be looked at by the researcher, where it is relevant to my taking part in this research (for example, to get a contact address, age or confirm clinical information). I give permission for this individual to have access to my records for this purpose. ☐
6. I agree to take part in the above study. ☐

Name of participant

Date

Signature

8. I have explained the study to this participant and answered their questions honestly and fully. ☐

Name of researcher

Date

Signature

When completed, 1 copy for participant, 1 for researcher; 1 (original) to be kept in medical notes

SCALE FOR THE ASSESSMENT OF POSITIVE SYMPTOMS (SAPS)

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(SAPS variable format edition: 2000)

SAPS RATING SHEET

Complete Using: C: Current. E: Episode.

	Episode	Current
HALLUCINATIONS		
Auditory Hallucinations		
Voices Commenting		
Voices Conversing		
Somatic or Tactile Hallucinations		
Olfactory Hallucinations		
Visual Hallucinations		
<i>Global Rating Severity Hallucinations</i>		
DELUSIONS		
Persecutory Delusions		
Delusions of Jealousy		
Delusions of Sin or Guilt		
Grandiose Delusions		
Religious Delusions		
Somatic Delusions		
Ideas and Delusions of Reference		
Delusions of Being Controlled		
Delusions of Mind Reading		
Thought Broadcasting		
Thought Insertion		
Thought Withdrawal		
<i>Global Rating Severity Delusions</i>		
BIZARRE BEHAVIOR		
Clothing and Appearance		
Social and Sexual Behavior		
Aggressive and Agitated Behavior		
Repetitive or Stereotyped Behavior		
<i>Global Rating of Severity of Bizarre Behavior</i>		
POSITIVE FORMAL THOUGHT DISORDER		
(not rateable for worst episode)		
Derailment (Loose Associations)		
Tangentiality		
Incoherence (Word Salad, Schizophasia)		
Illogicality		
Circumstantiality		
Pressure of Speech		
Distractible Speech		
Clanging		
<i>Global Rating</i>		

- 0 None
- 1 Questionnaire
- 2 Mild
- 3 Moderate
- 4 Marked
- 5 Severe

SCALE FOR THE ASSESSMENT OF NEGATIVE SYMPTOMS

(SANS)

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(SAS Variable Name edition: 2000)

SANS

- Affective Flattening or Blunting**

	Not at all	Questionable decrease	Mild	Moderate	Marked	Severe
Unchanging Facial Expression	0	1	2	3	4	5
Decreased spontaneous movements	0	1	2	3	4	5
Paucity of expressive gestures	0	1	2	3	4	5
Poor eye contact	0	1	2	3	4	5
Affective nonresponsivity	0	1	2	3	4	5
Lack of vocal inflections	0	1	2	3	4	5
Global rating of affective flattening	0	1	2	3	4	5
Inappropriate affect	0	1	2	3	4	5

- Alogia**

	Not at all	Questionable decrease	Mild	Moderate	Marked	Severe
Poverty of speech	0	1	2	3	4	5
Poverty of content of speech	0	1	2	3	4	5
Blocking	0	1	2	3	4	5
Increased latency of response	0	1	2	3	4	5
Global rating of alogia	0	1	2	3	4	5

- Avolition-Apathy**

	Not at all	Questionable decrease	Mild	Moderate	Marked	Severe
Grooming & hygiene	0	1	2	3	4	5
Impersistence at work or school	0	1	2	3	4	5
Physical anergia	0	1	2	3	4	5
Global rating of avolition - apathy	0	1	2	3	4	5

- Anhedonia – Asociality**

	Not at all	Questionable decrease	Mild	Moderate	Marked	Severe
Recreational interests and activities	0	1	2	3	4	5
Sexual interest and activity	0	1	2	3	4	5
Ability to feel intimacy and closeness	0	1	2	3	4	5
Relationships with friends and peers	0	1	2	3	4	5
Global rating of anhedonia - asociality	0	1	2	3	4	5

- Attention**

	Not at all	Questionable decrease	Mild	Moderate	Marked	Severe
Social inattentiveness	0	1	2	3	4	5
Inattentiveness during mental status testing	0	1	2	3	4	5
Global rating of attention	0	1	2	3	4	5

Time Budget Measure

Name:.....

Date:.....

We are interested in finding out a bit more about how you spend your time. This would include activities outside the home, such as work, study, any groups or centres that you attend, how you spend your leisure time, as well as home-based things for example, watching TV, reading, cooking and housework.

I would also like to know about social activities- seeing or going out with friends, talking on the phone, chatting to neighbours or other people and so on.

Thinking about the past week, perhaps we could divide up each day and think about what you can remember doing? Has the past week been an average week for you?

M Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	R
T Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	R
W Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	R
T Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	R
F Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	R

[illegible]

1. Are any of the activities that you have just told me about things that you have recently taken up, or things that you had previously stopped doing but have recently restarted? By recently, I mean within the past six months? (go through each day of the week)

2. Are there any things that you are not doing at the moment, but have plans to do, or would like to do in the future?

3. Do you live with, or see a lot of, a family member or someone with whom you have a caring relationship? How much time each week do you spend in face to face contact with them?

4. How satisfied are you with what you have been doing in the past week on a scale of 1-5, with 1 = not satisfied, and 5 = very satisfied?

1 2 3 4 5

5. If you are not satisfied, what would need to happen to make you more satisfied?

Time Budget Measure

Introduction

This measure has been designed to assess activity levels, particularly for people with psychosis. It should be completed as a structured interview with respondents. It is designed to be individualised, and to be sensitive to change. Norms are given in:

Jolley S. Garety P. Dunn G. White J. Aitken M. Challacombe F. Griggs M. Wallace M. Craig T. (2005) A pilot validation study of a new measure of activity in psychosis. *Social Psychiatry & Psychiatric Epidemiology*. 40(11):905-11

Jolley, S., Garety, P.A., Ellett, L., Kuipers, E., Freeman, D., Bebbington, P.E., Fowler, D.G., & Dunn, G. (2006). A validation of a new measure of activity in psychosis. *Schizophrenia Research*. 85: 288-295.

The following guidelines should be read before administration.

1. The measure should be completed for a typical week (e.g. not one when the respondent was unusually unwell, or in hospital) unless an atypical week is particularly required.
2. Start the week with whatever 'yesterday' was – this should be easier for participants to remember. Prompt if memory is poor. Ask about any known activities, or activities emerging as a pattern (e.g. 'when did you get up'; 'did you have breakfast?'; 'what did you do then?'; 'you go to the day centre, don't you – did you do that in the afternoon?'). If the week is very repetitive, it is OK to say – was that morning the same? Anything different? Normalise lack of activity for some time periods, empathise with difficulties particularly if client is upset by lack of activity. Normalise difficulty remembering. Try to help the respondent as much as possible. See Appendix 1 for prompt questions.
3. Stick to usual times of day when determining which box to complete. For example, if the person does not get up until lunchtime, score the morning as sleeping (0) and fill in the rest of the day from lunchtime onwards. If the person goes to bed late with lots of evening activities, these should still go in the 'evening' box, and can only achieve a maximum score of 4.
4. All activities should be noted, without judgement. Even where activities are deemed inappropriate by the interviewer, these should still be added and scored. It is quite usual for people to have 0 and 1 scores for time periods in their week, even when functioning quite highly. E.g. common behaviours such as having a lie in will receive a 0, and watching TV a 1.
5. Complete the additional questions. Note new and resumed activities (Q1) in the relevant columns.
6. Each time period is given a score (Appendix 2). Scoring is based degree of planning, complexity and effort required.

Appendix I Prompt questions

To ensure accessing all activities:

Examples:

When did you get up?

What did you do then...next...after x...etc.?

What do you usually do at that time?

Is there anything going on in the hostel (or wherever lives) at that time?

To check for level of social contact:

Examples:

Was anybody with you then/ when you did that?

Did you see anyone else?

Did you talk to anyone while you were doing that/ there?

Face to face? On the phone?

To check level of involvement & effort:

Did you do that on your own?

(If with someone else determine role of other person)

Did you organise that yourself?

What did you have to do to do that (e.g. 'going to church' – does that involve a bus ride, meeting others, talking?)

Appendix II Scoring guidelines

0 – nothing – lying thinking, sleeping, sitting etc.

1 – predominantly passive activity. Watching TV, listening to radio, eating a meal prepared by someone else. Includes brief chatting with people who are already there (e.g. staff, group home or hostel), unless there is evidence that person actively sought out and engaged in company and conversation (see 2). Taking care of basic hygiene.

2- an independent activity requiring some planning and motivation, but relatively simple or brief. E.g. a walk to the local shops to get cigarettes, tidying room, washing- up, preparing a simple meal for oneself. Attending a group in a hostel. Accompanied group outing from a hostel. Social contact that does not require much planning – e.g. seeking out and talking to friend in a hostel; being visited, without any specific activity or preparation. Talking to people sitting with during lunch (if not in hostel or group home). Reading (e.g. browsing through the paper or a magazine, flicking through a book, or a brief period of involved reading). A phone call to someone.

3 – several 2-rated activities **completely filling** a time period, sounding ‘busy’ (e.g. got breakfast, washed up, got newspapers from shop, looked at papers, made coffee, got cigarettes from shop, tidied up, listened to music and chatted with friend in hostel, went out for milk for staff), or a more complex and demanding but unvaried or shorter activity. Examples: visiting somebody when this requires a journey but a limited range of activities – e.g. ‘went to Mum’s on bus’; e.g. ‘played computer bridge all morning’. Attending a day centre or rehabilitation centre. A trip out which takes time but may not be very demanding – e.g. ‘went to church’ for whole time period. E.g. ‘went to pub with friend’. e.g. preparing a complicated meal for self. Reading if lengthy and obviously goal directed (e.g. read a novel, or read something for course of study).

4 – time period filled with a variety of demanding independent activities requiring significant motivation and planning and with some variation in tasks. E.g. work, a course of study, a trip out requiring organisation - meeting people, transport, varied activities. E.g. ‘met friend went round shopping centre shopping together, went for lunch together’; e.g. ‘took tube into central London, went to museum, tea at café, walked around park’; e.g. ‘met friends, went to pub, went on to club, talking and dancing’.

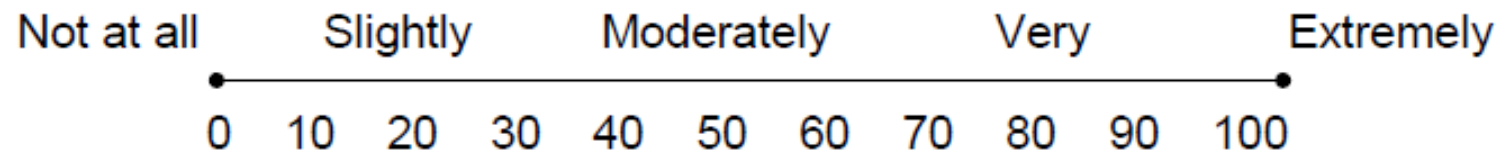
Computer activities

Time spent on the computer, X-Box etc. should be scored according to effort or involvement – just scrolling through internet pages, or playing a very repetitive game without much involvement would score a 2; playing a complex strategy games, or a similarly involving and effortful activity should score a three.

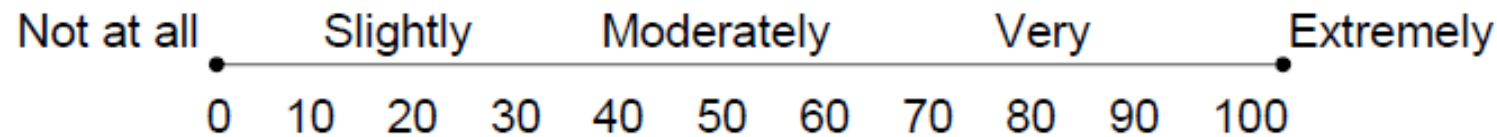
Suzanne Jolley January 2010, updated August 2010.

For each of the questions below, please put a vertical mark like this | through the horizontal line to indicate how you feel *right now*. The numbers are there as a guide.

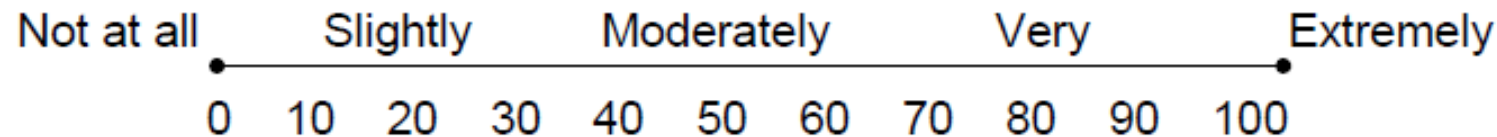
Please mark on the line below how **LONELY** you feel **RIGHT NOW**.



Please mark on the line below how **ANXIOUS** you feel **RIGHT NOW**.

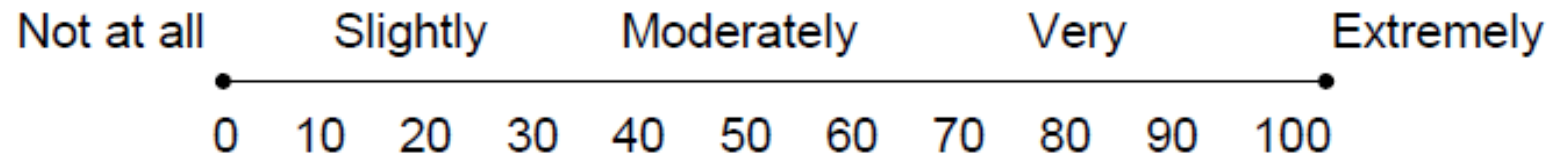


Please mark on the line below how **DISTRESSED** you feel **RIGHT NOW**.

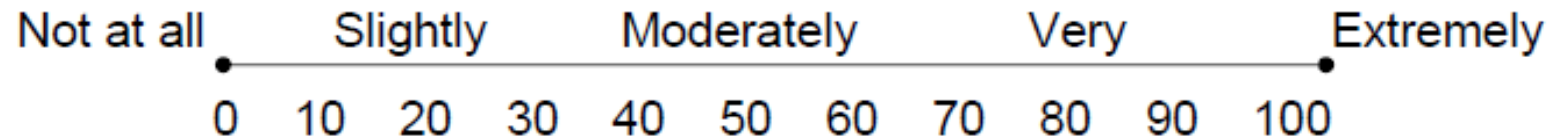


For each of the questions below, please put a vertical mark like this | through the horizontal line to indicate how you feel *right now*. The numbers are there as a guide.

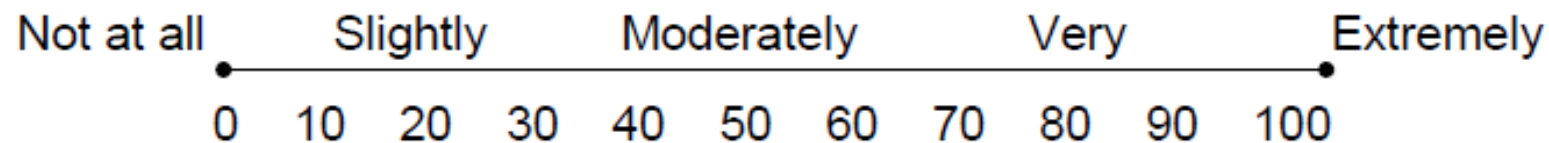
Please mark on the line below how **HAPPY** you feel **RIGHT NOW**.



Please mark on the line below how **PARANOID** you feel **RIGHT NOW**.



Please mark on the line below how **SAD** you feel **RIGHT NOW**.



Center for Epidemiologic Studies Depression Scale (CES-D), NIMH

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

	During the Past			
	Week			
	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I did not feel like eating; my appetite was poor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I felt that I could not shake off the blues even with help from my family or friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I felt I was just as good as other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I had trouble keeping my mind on what I was doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I felt hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I thought my life had been a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I felt fearful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I was happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I talked less than usual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I had crying spells.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I felt that people dislike me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I could not get "going."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SCORING: zero for answers in the first column, 1 for answers in the second column, 2 for answers in the third column, 3 for answers in the fourth column. The scoring of positive items is reversed. Possible range of scores is zero to 60, with the higher scores indicating the presence of more symptomatology.

THE MULTIDIMENSIONAL SUPPORT SCALE

The following questions concern the kind of help and support you have available to you in coping with your life at present.

- How many close friends or family have you seen in the past week (was this an average week)?

- Compared to a typical week would you say you saw more or less friends and family?

Less than usual

About the same as usual

More than usual

- Now think about **close friends and family members**, especially the 2-3 who are most important to you.

In the last month:

1a	How often did they really listen to you when you talked about your problems	Never	Sometimes	Often	Always
1b	And would you have liked them to do this...	More Often	Less Often	It was about right	
2a	How often did you feel that they were really trying to understand you?	Never	Sometimes	Often	Always
2b	And would you have liked them to do this...	More Often	Less Often	It was about right	
3a	How often did they make you feel loved?	Never	Sometimes	Often	Always
3b	And would you have liked them to do this...	More Often	Less Often	It was about right	
4a	How often did they help you in practical ways, like doing things for you or lending you money?	Never	Sometimes	Often	Always
4b	And would you have liked them to do this...	More Often	Less Often	It was about right	
5a	How often did they give you advice about your problems	Never	Sometimes	Often	Always
5b	And would you have liked them to do this...	More Often	Less Often	It was about right	
6a	How often could you use them as examples of how to deal with problems?	Never	Sometimes	Often	Always

Appendix B6

6b	And would you have liked them to do this	More Often	Less Often	It was about right	
----	--	------------	------------	--------------------	--

6.3 Now, think about the **doctor and/or psychiatrist** who has been helping to take care of you.

In the last month:

1a	How often did they really listen to you when you talked about your problems	Never	Sometimes	Often	Always
1b	And would you have liked them to do this...	More Often	Less Often	It was about right	
2a	How often did you feel that they were really trying to understand you?	Never	Sometimes	Often	Always
2b	And would you have liked them to do this...	More Often	Less Often	It was about right	
3a	How often did they help you in practical ways, for example by being available when needed, or helping you to get other services?	Never	Sometimes	Often	Always
3b	And would you have liked them to do this...	More Often	Less Often	It was about right	
4a	How often did they give you advice and information?	Never	Sometimes	Often	Always
4b	And would you have liked them to do this...	More Often	Less Often	It was about right	
5a	How often could you use them as examples of how to deal with problems	Never	Sometimes	Often	Always
5b	And would you have liked them to do this...	More Often	Less Often	It was about right	

- *On how many days did you feel lonely and in need of companionship during the last week*
- *Do you have someone you can confide in?*
Yes
No

Picture	Anxiety picture	Neutral / happy picture
1	Man cut off by car	Boy sitting at desk
2	Man pointing gun	Boy standing at lake
3	Masked man with knife	Ice cream parlour
4	Man attacking woman	Men sweeping floor
5	Man covered in blood	Boy drying hair
6	Bleeding woman in car	Campers outside tent
7	Man staring at woman	Business men at table
8	Junkie injecting heroin	Children chasing ball
9	Spider on man's shoulder	Business lunch
10	Plane crash	Man sitting under parasol
11	Firemen rescuing woman from burning house	Surfers
12	Noose	Boy walking with parents
13	Gun pointing	Dog at lake
14	Man threatening woman with knife	Farm house
15	Man pointing gun to own head	Swimming pool

Part 2: Service Evaluation Project

Psycho-social and functional outcome
after neurological recovery from
subarachnoid haemorrhage (SAH) – the
need for a psychology service

Supervisor:

Dr. Lidia Yáguez

Abstract

The aim of this service project was to evaluate psycho-social outcome after neurological recovery from subarachnoid haemorrhage (SAH) in a South London hospital (King's College Hospital) and discuss the need for neuro-psychology services for this particular client group.

Outcome was assessed for 118 SAH patients at 6 months post-surgery. Following SAH a high proportion of patients suffered from mental health difficulties and other psycho-social problems, such as day to day management of their lives, concentrating or dependence on others.

The study highlights a significant shortage of community based neuropsychology services for patients from the King's College Hospital catchment area who survive SAH and are likely to experience emotional and functional difficulties (approximately 150 patients each year).

Two main suggestions are put forward to inform service development in the KCH catchment areas. First, routine follow-up assessment of patients after SAH should include a self-report health measure (e.g. the SF-36) in order to improve identification of those in need of psychology help. Second, the boroughs of Lambeth, Lewisham and Southwark should establish clinical neuropsychology services in the community. Putting these recommendations into practice would help to improve identification and treatment of those in need of psychological help following brain damage such as SAH.

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1 Introduction

1.1 Purpose

This service evaluation project evaluates psycho-social and functional outcome of patients who have recently suffered subarachnoid haemorrhage (SAH) and shown good neurological recovery. The need for a psychology service for this client group is discussed.

1.2 Definition

SAH is a bleed into the subarachnoid space between the arachnoid layer and the cortical surface of the brain. The subarachnoid space comprises essentially the basal cisterns, the interhemispherical fissure and the Sylvian fissure (Yasargil, 1984). SAH is a form of stroke and comprises 1–7% of all strokes (Linn, Rinkel, Algra, & Van Gijn, 1998). Figure 1 shows an image of SAH in the centre of the brain.



Figure 1CT brain scan illustrating SAH as a white area in the centre of the brain and stretching into the Sulci to either side (arrow)¹.

¹ Source: <http://en.wikipedia.org/wiki/File:SubarachnoidP.png>

1.3 Epidemiology, risk factors and outcome

The overall prevalence rate of SAH is approximately 9 per 100.000 persons annually (Molyneux & others, 2002). However, rates vary significantly by region, with doubled rates in Japan and Finland and far lower rates in South and Central America (de Rooij, Linn, van der Plas, Algra, & Rinkel, 2007). Incidence rates are significantly higher in women (approx 1.6 times) than in men and increase with age (Linn et al., 1998). Risk factors include smoking, arterial hypertension, and excessive alcohol (Feigin, Rinkel, Lawes, Algra, Bennett, van Gijn, & Anderson, 2005b). Furthermore, familial predisposition is highly associated with increased risk of SAH, i.e. between 5-20% of SAH patients have a positive family history (Schievink, 1997).

Causes of spontaneous SAH vary, but in 50% of all cases SAH is caused by a ruptured cerebral aneurysm. Other causes include hypertension / arteriosclerosis (15%), arteriovenous malformation (6%), multiple causes (6%), 15 - 25% of the bleedings remain without a proven source (Linn et al., 1998).

1.4 Diagnosis and clinical features of SAH

The most prominent feature of SAH is a severe and devastating headache with rapid onset (“thunderclap headache”). Other symptoms include vomiting, confusion or a lowered level of consciousness ranging from a clouding of consciousness to deep coma (Van Gijn & Rinkel, 2001). A CT scan of the brain is the most important clinical tool in confirming the diagnosis.

1.5 Treatment and Management of SAH

Once the diagnosis is confirmed, immediate neurosurgery of the aneurysm is the most important available treatment. To reduce the risk of further bleeding two treatment forms are currently available: clipping and coiling. *Clipping* is a surgical operation during which the skull is opened to locate the aneurysm which is then clipped around its neck (REF). *Coiling* refers to blocking off the aneurysm through the large blood vessels (endovascular) (REF). In contrast to clipping, coiling does not require open surgery. Instead, using real-time X-ray, surgeons insert a catheter into the femoral artery in the patient’s leg and advance it through the vascular system into the head and into the aneurysm. When the

aneurysm is located, platinum coils are deployed blocking blood flow into the aneurysm thus preventing rupture (REF). The decision as to whether to treat the patient using coiling or clipping is typically made by a multidisciplinary team consisting of a neurosurgeon, neuroradiologist and often other health professionals. A recent RCT (Molyneux & others, 2002) found that after coiling the number of people who survive and are independent in their daily living is higher than after clipping. The main drawback of coiling is the possibility that the aneurysm will recur; this risk is extremely small in the surgical approach (Molyneux & others, 2002).

1.6 Outcome

Outcome after SAH is generally poor (Hop, Rinkel, Algra, & van Gijn, 1998); up to 15% of patients die before reaching a hospital and half of patients die within one month; although survival trends are improving (Hop, Rinkel, Algra, & van Gijn, 1997). However, even those who show good neurological recovery often have poor quality of life (Hop et al., 1998). Just under half of the patients remain dependent on someone else for help with activities of daily living such as walking, dressing, and bathing; and only fewer than 20% have no residual symptoms (Molyneux & others, 2002). The impact of SAH on the patient's psycho-social wellbeing is described in the next section.

1.7 Psycho-social sequelae after good neurological recovery of SAH

Patients who show good neurological recovery are usually discharged back into the community and not followed-up. However, recent research shows that SAH patients who have shown good neurological recovery do indeed show a broad range of psycho-social impairments (Powell, 2002). A number of studies following up patients after SAH found relatively high rates of psychological distress and impaired social functioning up to 10 years post-surgery (Freckmann, Stegen, & Valdueza, 1994; Mangold & Wallenfang, 2000; Wermer, Kool, Albrecht, Rinkel, & others, 2007). For example, Freckmann et al. (1994) noted high rates of mood disturbance and loss of social contact in patients with good physical and cognitive outcomes. Furthermore, a number of studies have consistently found high rates of anxiety and depression in neurologically recovered SAH patients (e.g. Mangold & Wallenfang, 2000). A recent study by Wermer et al. (2007) extended these findings by showing that despite neurologically good recovery a significant proportion of

patients have reduced employment rates, experience more relationship problems and break-ups due to SAH-related problems; and also report more frequent changes in personality, especially increased irritability (Ahola, Vilkki, & Servo, 1996; Hütter, Gilsbach, & Kreitschmann, 1995).

Overall, a third to a half of SAH patients suffer from neuro-psychiatric and psychosocial problems (Politynska, Berrios, & Lewko, 1995). Explanations for psycho-social problems after neurological recovery from SAH vary. For example, it has been suggested that organic brain injury stemming either from the bleeding itself or from lesions caused by the operation results in neuropsychological impairments that either directly or indirectly underlie the observed mood changes and functional problems (Hütter & Gilsbach, 1992; Ljunggren, Sonesson, Säveland, & Brandt, 1985; Storey, 1967). Conversely, Ogden et al. (1993) have suggested that psychological stress is a predisposing factor for SAH, thus raising the possibility that at least some of the psychosocial problems observed after SAH may have been present before onset.

The majority of studies reviewed above were cross-sectional, without non-neurological comparison groups, and involved retrospective interviews at variable time periods after the SAH. Therefore they are unable to distinguish between these two possible explanations. In an attempt to further clarify the temporal relationship between the occurrence of SAH and subsequent psycho-social disturbances, Powell and colleagues (2002) conducted a longitudinal study looking at psycho-social outcomes after SAH at 3 and 9 months post-surgery. In line with the bulk of cross-sectional studies reviewed above the authors found that SAH patients showed increased mood disturbance, subtle cognitive impairment and abnormally low independence and participation on measures of social functioning. The authors highlight the need for structured support and treatment after SAH surgery to reduce persisting mood disturbance and increase independence and participation.

As outlined above, a significant proportion of SAH patients with good neurological recovery develop severe and persistent ongoing psycho-social impairments. After discharge to the community these patients are usually not followed-up and left to cope alone.

1.8 Service Evaluation Project

The overall aim of this service project is to evaluate psycho-social outcome after good neurological recovery from SAH in a South London hospital and discuss which services are needed for this particular client group.

2 Method

2.1 Design

The study uses a prospective longitudinal design. Patients who had been treated in the neuro-vascular service at King's College Hospital for SAH and made good neurological recovery were contacted again at 6 months post-surgery to assess psycho-social and physical outcome.

2.2 Participants

All patients (N=118, 80 females) were treated at King's College Hospital in the London Borough of Southwark. This hospital serves a population of 700,000 from the boroughs of Southwark, Lambeth and Lewisham but also serves as a tertiary referral centre in certain specialties to millions of people in southern England.

2.3 Data collection and procedure

Data was collected between October 2009 and October 2010. All patients who received neurosurgical treatment for SAH (clipping or coiling) were sent by the Specialist Nurse the SF-36 six months post-surgery. Response rate was 55%, which is comparable to other general health studies (Barclay, Todd, Finlay, Grande, & Wyatt, 2002; Brazier et al., 1992).

Data was collected at two time points: T1 and T2. T1 refers to the time of the admission; T2 indicates the follow-up time point approximately 6 months after treatment.

The **World Federation of Neurological Surgeons (WFNS)** grading system was administered at T1 the rest of the questionnaires and measurements were administered at T2.

2.4 Description of questionnaires

The following section provides a brief overview of the measures used in this project.

The **World Federation of Neurological Surgeons (WFNS)** grading system is one of the most commonly used grading scales to assess severity of SAH. The grading system is intended to be a simple, reliable and clinically valid way of grading a patient with SAH. The WFNS Scale is based on the Glasgow Coma Scale (GCS) and on the finding of a motor focal deficit (Drake et al., 1988). The GCS is a commonly used neurological scale that aims to give a reliable, objective way of recording the conscious state of a person for initial as well as subsequent assessment. Three types of response are measured, and added together to give an overall score. The three responses measured are: best motor response with a maximum score of 6, best verbal response with a maximum score of 5, and eye opening with a maximum score of 4. The lower the score the lower the patient's conscious state. A GCS of 8 or less indicates severe injury, one of 9-12 moderate injury, and a GCS score of 13-15 is obtained when the injury is minor.

The WFNS scale is as follows:

Grade	Glasgow Coma Score	Motor Deficit
1	15	Absent
2	13 – 14	Absent
3	13 – 14	Present
4	7 – 12	present or absent
5	3 – 6	present or absent

A grade of 1-2 is considered good grade, a grade of 3-5 is considered as poor grade.

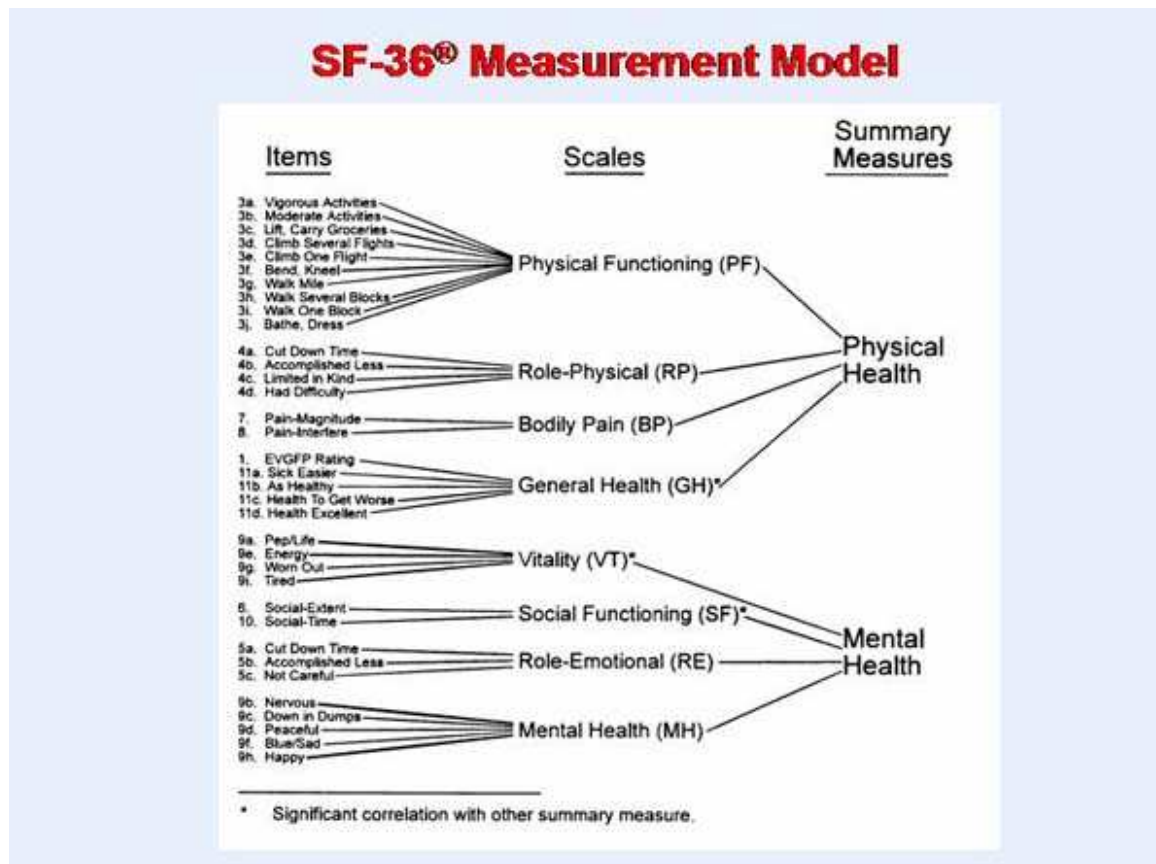
The **Glasgow Outcome Scale – extended (GOSE)** (Wilson, Pettigrew, & Teasdale, 1998) is an 8-point score given to survivors of brain injury to assess their general functioning. The GOS reflects functioning rather than impairment, i.e. the scale focuses on how the injury has affected functioning in major areas of life rather than on the particular deficits and symptoms caused by injury (World Health Organization, 1980). It gives a general index of overall outcome. The GOSE extends the original 5 GCS categories to 8. The scale is often used to quantify the level of recovery patients have achieved. The GOSE is determined by a clinician at some point in the patient's recovery. The GOSE scale is as follows:

GOSE		
score	Performance level	Dichotomous outcome
1	Upper good recovery Good recovery	Favourable outcome
2	Lower good recovery Good recovery with minor social or mental deficits	
3	Upper moderate disability Able to return to work at reduced capacity, reduced participation in social activities	
4	Lower moderate disability Unable to return to work or participate in social activities	
5	Upper severe disability Dependent on others for some activities	Unfavourable outcome
6	Lower severe disability Completely dependent on others	
7	Severely disabled Either pre-haemorrhage or for some other reason not related to the haemorrhage.	
8	Dead	

A score of 1-4 is considered as favourable outcome; a score of 5-8 is considered as an unfavourable outcome.

The SF-36 (Brazier et al., 1992) is a 36 item measure of general health and yields an 8-scales profile of functional health and well-being scores in addition to two summary measures, the mental component summary (MCS) and the physical component summary (PCS). The MCS summarises the subscales of Vitality, Social Functioning, Role-Emotional, and Mental Health (MH), whereas the PCS summarises the subscales Physical Functioning, Role-Physical, Bodily Pain, and General Health. The taxonomy of the SF36 is illustrated in Figure 2. The taxonomy has three levels: (1) items; (2) eight scales that aggregate 2-10 items each and (3) two summary measures that summarise the scales.

Figure 2 Taxonomy of the SF36



The SF-36 has good psychometric properties. The reliability (both re-test and internal consistency) of the eight scales exceeds 0.80 (McHorney et al., 1994; Ware et al., 1993) whereas reliability estimates for the physical and mental summary scores usually exceed 0.90 (Ware et al., 1994)

Construct and empirical validity for the SF-36 are high (McHorney et al., 1993; Ware et al., 1994; Ware et al., 1995). The scales comprising in the physical summary score respond mostly to treatments that target physical health, whereas the scales forming the mental summary score are mostly responsive to treatments targeting mental health. Both summary scores explain 80-85% of the variance in the eight scales (Ware et al., 1994).

The MH scale has been shown to be useful in screening for psychiatric disorders (Berwick, 1991; Ware et al., 1994), as has the MCS summary measure (Ware et al., 1994). For

example, using a cut-off score of 42, the MCS had a sensitivity of 74% and a specificity of 81% in detecting patients diagnosed with depressive disorder (Ware et al., 1994).

Scores on the MH scale range from 0 to 100 (with high scores indicating better mental health) and on the MCS from 0 to 81. Scores \leq **52 on the MH** – ‘are indicative of emotional problems probably of any psychiatric disorder’ – and \leq **42 on the MCS** – ‘are indicative of clinical depression’. These cut-offs are used in this study.

2.5 Ethics

Ethical approval was granted by King’s College Hospital Ethics committee. Data were acquired as part of a routine follow-up assessment.

3 Results

All data was analysed using SPSS 15.0 (SPSS Institute, Chicago, IL, USA).

3.1 Descriptive statistics

T1: Admission to hospital

Table 1 provides descriptive statistics for age and duration of hospital stay, displayed separately for females and males. Average age was 51.53, and average stay was 20.5 days. Neither gender differed in age or duration of stay ($t(116)=.23$; $p=.82$).

Table 1 Age and duration of stay, according to gender

Gender	Age M (SD)	Duration of stay in hospital (in days) M (SD)
Female (N=80)	51.70 (11.6)	20.8 (10.0)
Male (N=38)	51.16 (12.8)	19.9 (9.0)
Total (N=118)	51.53 (11.98)	20.5 (9.7)

Table 2 describes the neurological condition on admission based on the WFNS grading system for both genders. In total, 95 (86.3%) patients obtained a good grade of either 1 or 2. Fifteen patients (13.7%) received a poor grade of 3 or worse indicating poor functioning. Women tended to have a poorer WFNS grade than men ($\chi^2(4) = 7.56$, $p=.099$). Data for 8 patients is missing in this analysis.

Table 2 World Federation of Neurological Surgeons (WFNS) grading scale for Subarachnoid Haemorrhage (SAH), for both males and females at time of admission.

	Gender		
WFNS	Female	Male	Total (%)
Grade 1 (GCS 15) no neuro deficit	52	29	81 (73.6)
Grade 2 (GCS 13 - 14) no neuro deficit	7	7	14 (12.7)
Grade 3 (GCS 13 - 14) with neuro deficit	7	0	7 (6.4)
Grade 4 (GCS 7 - 12) present or absent	3	1	4 (3.6)
Grade 5 (GCS < 7) present or absent	4	0	4 (3.6)
	73	37	110

T2: 6 months after SAH

Table 3 shows the distribution of the Glasgow Coma Outcome Scale Extended (GOSE) scores at 6 months follow-up. The majority of patients made a favourable neurological recovery (N=82, lower moderate disability or above), and only 11 patients had an unfavourable outcome (upper severe disability or below). There is no difference between genders on the GOSE ($\chi^2(5) = 1.91$, $p = .878$). Data for 20 patients is missing in this analysis.

Table 3 Glasgow Outcome Scale Extended for both genders at 6 months follow-up

	Gender		
Glasgow Outcome Scale Extended	Female	Male	Total (%)
Upper good recovery	36	15	51 (52)
Lower good recovery	8	3	11 (11.2)
Upper moderate disability	15	5	20 (20.4)
Lower moderate disability	3	2	5 (5.1)
Upper severe disability	4	1	5 (5.1)
Lower severe disability	3	3	6 (6.1)
	69	29	98

Table 4 displays descriptive statistics for the subscales of the SF-36 as well as the two summary scores, the MCS and the PCS at 6 months post-surgery. Means of the normative sample are 50, with a standard deviation of 10. The “Mental Health” and the “Mental Component Summary” scores are highlighted since they are the main focus of this study. All patients from this sample (N=118) had filled in the SF-36. On average patients obtained scores close to the population mean on all subscales as well as composite scores. However, there is a strong variation across patients and subscales thus indicating that at least some patients suffer from very poor physical and mental health.

Table 4 Descriptive statistics of the SF-36 at 6 months after neurosurgery

	N	Min	Max	Mean	Standard Deviation
General Health	118	21.00	63.90	46.97	11.62
Physical functioning	118	14.94	57.03	44.85	11.97
Role limitation due to physical problems	118	17.67	56.85	42.10	12.70
Bodily Pain	118	24.93	62.12	49.12	12.08
Vitality	118	20.87	70.82	46.30	12.71
Social functioning	118	13.22	56.85	43.59	13.48
Mental Health	118	10.58	64.09	46.05	13.08
Role limitation due to emotional problems	118	9.23	55.88	42.32	14.52
Mental Component Summary	118	9.4	63.2	44.4	13.85
Physical Component Summary	118	13.16	62.89	46.30	11.19

The distribution of the “Mental Health” and the “Mental Component Summary” scores is illustrated in Figure 3 (MH) and Figure 4 (MCS). Higher scores indicate a better mental health. Patients scoring below the cut-off are likely to suffer from mental health difficulties such as depression or anxiety, whereas patients scoring above the cut-off are more likely to be unaffected. Overall, 64 (54.2%) patients obtained a MH score lower than 52 suggesting that these patients may suffer from some emotional problems / psychiatric disorder.

Similarly, 45 (38.1%) patients scored lower than 42 on the MCS indicating that they may suffer from clinical depression.

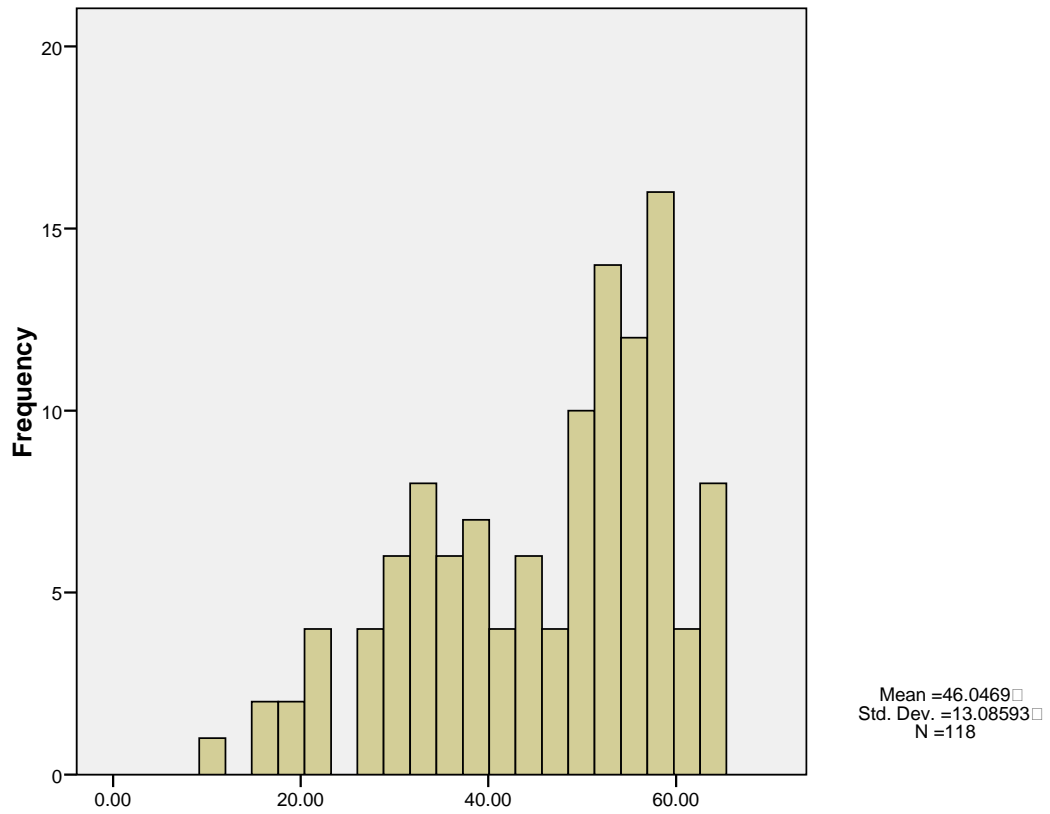


Figure 3 Distribution of MH score across the sample. Scores below 52 suggest that the client may suffer from emotional problems / psychiatric disorder.

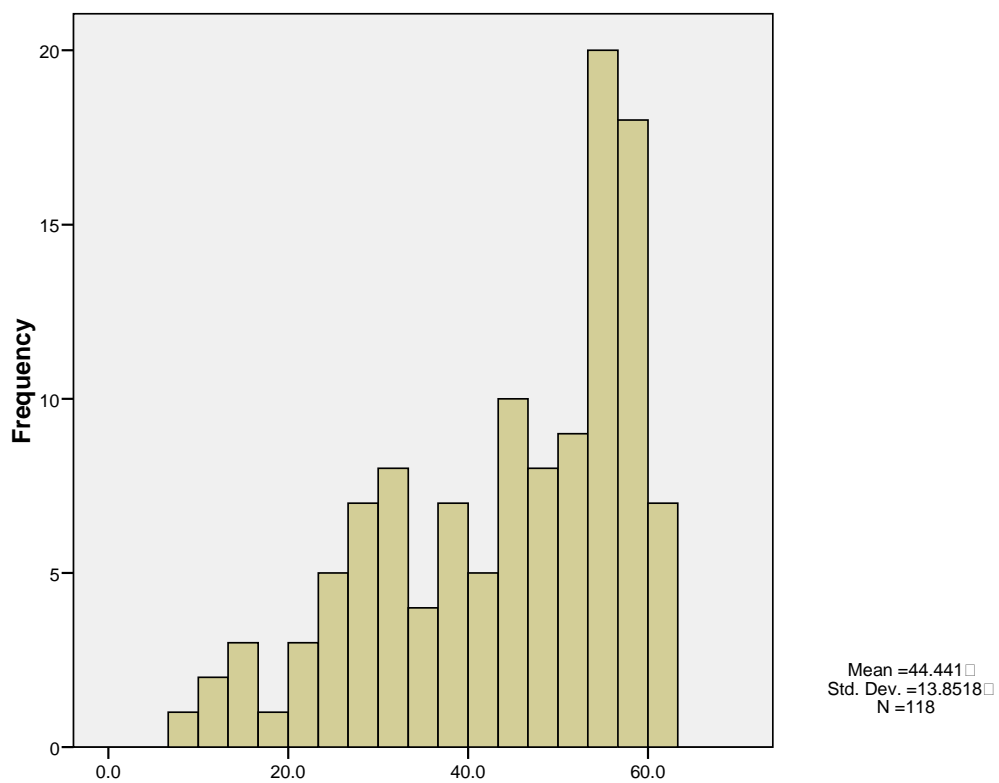


Figure 4 Distribution of MCS score. Scores below 42 indicate that the patient may suffer from clinical depression or anxiety.

Table 5 shows the correlations between the 8 subscales and the two component summary scores. All subscales significantly correlate with both component summary scores. Zero-order correlations of all subscales with the two component summary scores are highly significant with correlations ranging from 0.39 to 0.94. As would be expected from the underlying factor structure, physical health subscores load highest on the physical component score, whereas mental health subscores load highest on the mental component summary score.

Table 5 Correlation of subscales of the SF-36 with the two component summary scores.

	Mental Component Summary 6m	Physical Component Summary 6m
General Health	.67**	.70**
Physical functioning	.47**	.90**
Role limitation due to physical problems	.61**	.83**
Bodily Pain	.47**	.85**
Vitality	.73**	.65**
Social functioning	.87**	.59**
Mental Health	.94**	.39**
Role limitation due to emotional problems	.86**	.51**

** Correlation is significant at the 0.01 level (2-tailed).

3.2 Differences between patients with and without emotional difficulties at 6 months

The following section compares those patients with a MCS score of 42 or lower (indicative of an emotional disorder) with those scoring above it on a number of variables. For these analyses a dichotomous variable was created according to this cut-off.

Table 6 illustrates the distribution of the GOSE score below and above the cut-off of the “Mental Component Summary” score (MCS). As would be expected, patients who had a favourable outcome on the GOSE were more likely to score above the cut-off on the MCS ($\chi^2(5)=13.73$, $p=.017$). Although outcome has been assessed as favourable by the clinician on the GOSE for most patients (lower moderate disability or above, $N=87$), a substantial number of patients score below the cut-off ($N=38$) suggesting that they may suffer from clinically significant mental health problems. Data from the GOSE is missing for 20 patients.

Table 6 Distribution of Glasgow Outcome Scale Extended below and above the MCS cut-off.

Glasgow Outcome Scale Extended	MCS		
	below 42	above 42	Total (%)
Upper good recovery	12	39	51 (52)
Lower good recovery	4	7	11 (11.2)
Upper moderate disability	11	9	20 (20.4)
Lower moderate disability	3	2	5 (5.1)
Upper severe disability	4	1	5 (5.1)
Lower severe disability	4	2	6 (6.1)
Total	38	60	98

Table 7 compares the two groups on treatment modalities (clipping vs. coiling). As would be expected from the literature, more SAH patients were treated with coiling (75.4%) than with clipping. Of this sample, 45 patients score below the MCS cut-off with more patients reporting emotional difficulties at follow-up after clipping (44.8%) vs. coiling (36%); however, this difference in treatment modality is statistically not significant ($\chi^2(1)=.73$, $p=.509$).

Table 7 Comparison of treatment modality (clipping vs. coiling) below vs. above the MCS cut-off.

	MCS		
Treatment modality	Below 42	Above 42	Total (%)
Coiled	32	57	89 (75.4)
Clipped	13	16	29 (24.6)
Total	45	73	118

Table 8 compares the two groups on gender. Females appear to be more likely to score below the MCS cut-off than men (42.5% vs. 33.3%), however this gender difference is statistically non-significant ($\chi^2(1)=.37$, $p=.685$).

Table 8 Distribution of gender below and above the MCS cut-off.

	MCS		
Gender	Below 42	Above 42	Total (%)
Female	32	48	80 (67.2)
Male	13	25	38 (32.8)
Total	45	73	118

Table 9 contrasts the two groups with regard to complications experienced during treatment. The majority of patients had suffered at least one complication during surgery (75.5%) and only a quarter did not experience any complications during surgery (24.5%). Those patients with complications during surgery appeared to be more likely to fall below the MCS cut-off than those without complications (30.8% vs. 47.5%); however this difference was statistically non-significant ($\chi^2(1)=1.18$, $p=.290$). Note, data for 65 patients is missing in this analysis.

Table 9 Comparison between those who experienced complications during surgery and those without complications on the MCS.

	MCS		
Complications	Below 42	Above 42	Total (%)
No complications during surgery	4	9	13 (24.5)
At least one complication during surgery	19	21	40 (75.5)
Total	23	30	53

Table 10 compares patients who had one aneurysm with those who presented with one or more aneurysms. Twenty one patients presented with a single aneurysm and 61 patients had suffered multiple aneurysms. Multiple aneurysms tended to be associated with more mental health difficulties at 6 months post-treatment than single aneurysms (57.1% vs. 37.1%; $\chi^2(1)=2.59$, $p=.10$). Note, data for 36 patients is missing in this analysis.

Table 10 Comparison between those who had single aneurysms and those who suffered multiple aneurysms on the MCS.

	MCS		
Number of aneurysms	Below 42	Above 42	Total (%)
Single	12	9	21 (25.3)
Multiple	23	39	61 (74.7)
Total	35	48	82

Table 11 compares the two groups with regard to the location of their aneurysm. Forty seven patients presented with a right-sided aneurysm and 32 patients with a left-sided aneurysm. No statistical group difference was found with regard to the MCS ($\chi^2(1)=.24$, $p=.63$) thus suggesting that the side of the aneurysms is not predictive of mental health difficulties post-surgery. Data for 39 patients is missing in this analysis.

Table 11 Cross tabulation of side of aneurysm with MCS below and above cut-off.

	MCS		
Side of aneurysm	Below 42	Above 42	Total (%)
Right	18	29	47 (59.5)
Left	14	18	32 (40.5)
Total	32	47	79

Table 12 contrasts the two groups on the continuous variables “age” and “length of stay in hospital”. Groups did not differ on either of the two variables. The average age of this sample is 51, and there is no age difference between people scoring below or above the MCS cut-off ($t(116)=-.29$, $p=.78$). People scoring above the MCS cut-off tended to stay longer in hospital (22.8 days) than those scoring below the cut-off (18.8 days; $t(74)=1.80$, $p=.076$). Note, data for 32 patients is missing for the latter analysis.

Table 12 Comparison between patients scoring above and below the MCS cut-off, on the variables “age” and “length of stay in hospital”.

	MCS		
	Below 42	Above 42	
	Mean (SD)	Mean (SD)	Total
Age	51.1 (10.9)	51.8 (12.6)	51.5 (12)
Length of stay (in days)	18.8 (8.9)	22.8 (10.3)	20.5 (9.6)

3.3 Which variables predict Mental Health Difficulties at 6 months?

It would be desirable to identify those SAH patients who are likely to suffer from mental health difficulties following surgery. All variables obtained in the hospital were entered into a step-wise regression model to predict mental health outcome 6 month post-surgery (MCS). Those variables that significantly predicted the MCS were kept in the model; those that were non-significant were dropped. “Single aneurysm” was the only variable that significantly predicts the MCS: Patients with one aneurysm ($M=45.58$, $SD=11.9$) have a significantly higher MCS than those with multiple aneurysms ($M=36.6$, $SD=17.48$; $Beta=.28$, $T=2.64$; $p=.04$).

4 Discussion

This service evaluation project examined psycho-social and functional outcomes after SAH. Before discussing the main findings and outlining implications for services, the sample is briefly discussed

Descriptives

This study used a representative sample of 118 SAH patients who were treated at King's College Hospital London. In line with previous studies (Ayala et al., 2002; Feigin, Rinkel, Lawes, Algra, Bennett, van Gijn, & Anderson, 2005b; Powell, 2002), female gender appeared to be a significant risk factor for suffering SAH with prevalence rates for women being twice as high as for men. The average age in this sample was 51 thus confirming that onset of SAH is significantly earlier than onset of other strokes (Feigin, Rinkel, Lawes, Algra, Bennett, van Gijn, & Anderson, 2005a). On average, patients stayed 20 days in hospital for treatment and watchful waiting since risk of re-bleeding is particularly high in the days following SAH. To reduce risk of re-bleeding from the same cerebral aneurysm, patients were either treated with endovascular coiling or surgical clipping. In line with current treatment recommendations, the majority of SAH patients (3/4) were treated with coiling. This is because mortality rates and functional outcome (e.g. being dependent on others) after coiling have been found to be better than after clipping (Molyneux & others, 2002).

Psychosocial difficulties after SAH

This study confirms high incidence rates of mental health difficulties after SAH (e.g. Hütter & Gilsbach, 1992; Hütter et al., 1995; Powell, 2002) with 35% of the sample (45 out of 118) reporting clinically significant levels of anxiety and depression 6 months after their treatment. This incidence rate is more than twice as high as one would expect in the general population (Powell et al., 2003). These difficulties were not picked up by the routine assessment carried out by the neuro-surgeons 6 months post-surgery. In fact, outcome was assessed as favourable on the GOSE for most patients (N=87); nevertheless, a large number of patients reported significant functional problems in general and mental health difficulties in particular. This discrepancy between routine neurological clinical assessment at

follow-up and the SF-36 self-report measure raises the question as to whether functional and mental health difficulties are adequately detected in this client group. A number of reasons are conceivable to explain this discrepancy. Firstly, outcome assessment on the GOSE may not adequately assess these problems given the lack of reliability due to the unstructured nature and short format of the interview (Anderson, Housley, Jones, Slattery, & Miller, 1993; Maas, Braakman, Schouten, Minderhoud, & van Zomeren, 1983). Secondly, neurosurgeons may not have the specific skills necessary to assess for mental health difficulties. Thirdly, heavy time constraints which are the norm rather than the exception in large and hectic NHS hospitals may not permit for a thorough assessment of the patients' psychological needs.

Besides mental health difficulties, patients also reported a multitude of other physical and functional difficulties on the subscales of the SF-36. A significant number of patients complained about general health problems, bodily pain, low vitality, as well as difficulties in their social functioning and role limitations due to their physical and emotional problems. These areas of difficulties were highly predictive of both the mental and physical summary scores. As one would expect from the underlying factor structure of the SF-36 physical health subscales were more predictive of the physical component summary score, whereas mental health subscores were more predictive of the mental component summary score.

Given the significant impact SAH has on the clients' physical and mental well-being, clinicians should be particularly alert to difficulties in the above described areas of well-being and functioning. For example, if the patient presents with poor health or significant pain, the likelihood is very high that this patient also suffers from mental health difficulties. The fact that a significant proportion of SAH patients with psycho-social difficulties have not been picked up by the clinicians at the follow-up assessment is concerning. The results from this study suggests that a simple and easy to administer self-report questionnaire such as the SF-36 questionnaire could help to close this gap and thus improve identification of patients with mental health and functional problems.

Having a better understanding of who is likely to suffer from mental health difficulties following SAH could help to improve identification of those patients in need of

psychological support. Therefore, this study also looked at the differences between SAH patients with and without mental health difficulties and investigated which variables predict mental health status at follow-up. We compared those SAH patients with and without reported mental health difficulties on the SF-36 on a number of variables (gender, age, length of stay, treatment modality, complications during surgery, number and side of aneurysm) in order to identify potential risk variables. Number of aneurysms was the only significant predictor of mental health difficulties at 6 months follow-up; i.e. those patients who had suffered more than one aneurysm were more likely to report mental health difficulties 6 months post surgery. Groups did not differ on gender, age, side of aneurysms. Somewhat surprisingly, we also did not find group differences for treatment modality (clipping vs. coiling). Previous studies showed that coiling is associated with better psycho-social outcome than clipping (e.g. Powell et al., 2003). However, this study focused in particular on mental-health difficulties and it is conceivable that the association between other functional subscales of the SF-36 are more strongly associated with the variables under investigation. Alternatively, missing data may account for the lack of association between treatment modality and mental health difficulties.

Need for a psychology service

This project has demonstrated, in line with previous studies (e.g. Powell et al., 2003), that following SAH a high proportion of patients suffer from mental health difficulties and other psycho-social problems, such as day to day management of their lives, concentrating or dependence on others. The impact of these difficulties can be debilitating and adversely impact the clients' life. Common mental health difficulties after stroke such as mood disorder or anxiety require specialist psychology treatment and often require continuing care. Psychology services such as IAPT are increasingly accessible to the general public but may lack expertise knowledge in neuropsychology and cannot provide for the continuity of care. Depression after stroke may result as a consequence of adjusting to life whilst coping with the effects of the stroke, or depression may be a direct consequence from the neurological damage. Clinical neuropsychologists are best equipped with specialist knowledge which is necessary to adequately assess emotional difficulties following brain injury, inform formulation, develop coping and compensatory strategies, guide

rehabilitation goals and monitor ongoing recovery.

Therefore, the question arises what services are in place to adequately pick up and treat this client group. Patients from this sample were treated at KCH which covers 4 catchment areas, namely Lambeth, Southwark, Lewisham and Kent. Out of these, Kent is the only area which offers a clinical neuropsychology service to people after brain injury in the community (<http://www.kmpt.nhs.uk/clinicalneuropsychology>). This service provides neuropsychological assessment and continued care / rehabilitation to patients with acquired brain injury, including talking therapies for mood or anxiety difficulties following brain damage. On the other hand, there are no clinical neuropsychology services based in the communities of the boroughs of Lambeth, Southwark and Lewisham. However, a number of specialist and neuropsychology outpatient services are available such as the Lishman Unit or the Blackheath Brain Injury Rehabilitation Centre which provide assessment and treatment of adults with acquired brain injury, but cannot provide continued care. This shortage of community based neuropsychology services is extremely worrying given that each year approximately 300 patients from these areas survive SAH and half of them are likely to experience emotional and functional difficulties following their stroke. Since there are no appropriate services in the community, chances are very high that these difficulties remain unnoticed or, if other services do detect them (e.g. GP), symptoms may be misdiagnosed and treatment might be ill-informed.

This study makes two main suggestions to inform service development in the KCH catchment areas. First, routine follow-up assessment of patients after SAH should include a self-report health measure such as the SF-36 in order to improve identification of those in need of psychology help. Second, the boroughs of Lambeth, Lewisham and Southwark should follow Kent in establishing clinical neuropsychology services in the community. Putting these recommendations into practice would help to improve identification and treatment of those in need of psychological help following brain damage such as SAH.

Limitations

This project is not without limitations. First, data is missing for some of the variables thus limiting the generalisability of these findings. For example, the variable “complications during surgery” has only been recorded for 53 patients. This is due to the non-

systematic recording by the surgeons and should be addressed in future studies. Second, response rate of this project was rather low (55%), i.e. only half of the people who were contacted via mail after surgery sent back the SF-36. Hence, it is difficult to rule out that the present sample is not systematically biased. For example, it is possible that those patients who did not respond were more affected by the consequences of their SAH than responders or vice versa. However, response rates of this health survey were comparable to other general health studies (Barclay, Todd, Finlay, Grande, & Wyatt, 2002; Brazier et al., 1992). Future studies could possibly improve response rates by contacting patients directly in the hospital as opposed to sending out the questionnaire after discharge. Finally, it is important to note that this project did not measure incidence rates of specific diagnoses and, using the SF-36, only measured a subset of symptoms that are shared by anxiety and depressive symptoms. Hence, this study only offers a broad screening for mental health and functional outcome and it is therefore conceivable that prevalence rates of specific psychological difficulties such as posttraumatic stress disorder (PTSD) further increase the number of patients in need of psychology treatment following SAH. Future studies should study such specific psychological difficulties following SAH more closely in order to map out patients needs and consequently inform services more accurately.

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